

The logo for ELPA (European Liver Patients' Association) features the acronym 'ELPA' in a large, white, sans-serif font. The letters are partially overlaid by a light orange, irregular shape that resembles a liver. Below the acronym, the full name 'European Liver Patients' Association' is written in a smaller, white, sans-serif font.

ELPA

European Liver  
Patients' Association

# Empowering Journeys: Patient Engagement in Focus

**ANNUAL REPORT 2023**

**Empowering Journeys: Patient Engagement in Focus**

ANNUAL REPORT 2023

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## ACRONYMS

**ACHIEVE** - Associations Collaborating on Hepatitis to Immunise and Eliminate the Viruses in Europe  
**AASLD** - American Association for the Study of Liver Diseases  
**ACLF** - Acute-on-Chronic Liver Failure  
**AWARH** - Awareness Week on Alcohol-Related Harm  
**CEHC** - Central European Hepatologic Collaboration  
**CHB** - Chronic Hepatitis B  
**CSF** - Civil Society Forum  
**DG** - Directorate General  
**DiCE** - Digestive Cancers Europe  
**DILI** - Drug-Induced Liver Injury  
**EASL** - European Association for the Study of the Liver  
**ECDC** - European Centre for Disease Prevention and Control  
**ECPC** - European Cancer Patient Coalition  
**EF Clif** - European Foundation for the study of chronic liver failure  
**EIT** - European Institute for Innovation and Technology  
**EKPF** - European Kidney Patients' Federation  
**EMA** - European Medicine Agency  
**EMCDDA** - European Monitoring Centre for Drugs and Drug Addiction  
**EPF** - European Patients' Forum  
**ESCMID** - European Society of Clinical Microbiology and Infectious Diseases  
**ESMO** - European Society for Medical Oncology  
**ESPGHAN** - European Society for Paediatric Gastroenterology Hepatology and Nutrition  
**EU** - European Union  
**EURODIS** - Rare Diseases Europe  
**ETW** - European Testing Week  
**HBV** - Hepatitis B Virus  
**HCV** - Hepatitis C Virus  
**HDV** - Hepatitis D Virus  
**HE** - Hepatic Encephalopathy  
**HEP** - Hepatitis  
**HERA** - Health Emergency Preparedness and Response Authority  
**HTAI** - Health Technology Assessment International  
**ILC** - International Liver Congress  
**ILCA** - International Liver Cancer Association  
**LALD** - Lysosomal Acid Lipase Deficiency  
**LCAM** - Liver Cancer Awareness Month  
**MAFLD** - Metabolic-Associated Fatty Liver Disease  
**MoU** - Memorandum of Understanding  
**NAFLD** - Non-Alcoholic Fatty Liver Disease  
**NASH** - Non-Alcoholic Steatohepatitis  
**NGO** - Non-Governmental Organization  
**PCWP** - Patients' and Consumers' Working Party  
**PWID** - People Who Inject Drugs  
**SLTC** - Screening and Linkage to Care  
**TAG** - Technical Advisory Group  
**TB** - Tuberculosis  
**UNAIDS** - United Nations Programme on HIV/AIDS  
**VHPB** - Viral Hepatitis Prevention Board  
**WHO** - World Health Organisation



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# Our Mission

The European Liver Patients' Association - ELPA - emerged in 2005 from a desire amongst European liver patients groups to share their experiences on the different approaches adopted in other countries. Nowadays, ELPA is an umbrella association representing 32 members from 25 different countries.

ELPA aims to promote the interests of people with liver disease and, in particular: to highlight the size of the problem, to promote awareness and prevention, to address the low profile of liver disease; to share the experience of successful initiatives; to work with professional bodies to ensure that treatment and care are harmonised across Europe to the highest standards. ELPA's vision is that all liver patients are diagnosed in time, are treated with respect, and have equal access to the best standard of medical care – regardless of origin, lifestyle, and type of liver disease.

ELPA's efforts are focused on three main pillars.

## Member Empowerment

ELPA was established by patients, is governed by patients, and represents patients. We put much effort into organising training, promoting capacity building, and stimulating networking. We have eight different working groups to boost expert patients to acquire knowledge in a specific field of liver disease.

## Policy and Advocacy

As an umbrella patients' association, ELPA acts as an intermediary between all the involved stakeholders - the national patients' communities, the scientific community, the industry, and the policymakers. We provide a crucial perspective due to our immediate and direct access to the patients' lives and to the best practices in a national and regional context.

ELPA is a member of:

- Advisory forum and expert group on HBV and HCV at ECDC.
- Patient and Consumer Working Party and Pharmacovigilance Risk Assessment Committee at EMA.
- Policy and public health committee and Taskforce on liver cancer at EASL.
- Advisory Forum - Civil Society Forum at HERA.
- Expert group on HIV, TB, and hepatitis at WHO.
- Expert board at VHPB.

To better communicate with supporters and stakeholders, ELPA has obtained the ISO 9001:2015 quality standard in 2021, making it the 1<sup>st</sup> patients' association in Europe with a quality management system.

## Participation in Medical Research Projects

ELPA is part of 20 EU-funded medical research projects. The participation of patients' associations in these projects is relatively new; nevertheless, being part of them enriches the research field.

## ELPA Values



Equality



Respect for  
diversity



Patient  
driven



Commitment



Transparency



*ELPA Members, Group Picture*

# Foreword of the President

## **Dear Members, Partners, and Friends of ELPA,**

It is my honor to present the 2023 Annual Report of the European Liver Patient Association (ELPA). As we reflect on the past year's accomplishments and challenges, it is evident that our commitment to improving the lives of liver patients remains resolute.

In our relentless pursuit of this mission, ELPA has focused on three key pillars: members' capacity building, policy and advocacy, and scientific involvement.

Our strength lies in the collective power of our members. This year, ELPA has continued its dedication to enhancing the capacities of our member organizations. Through targeted programs, workshops, and collaborative initiatives, we have equipped our members with the knowledge, skills, and resources needed to provide optimal support to liver patients across Europe.

ELPA is steadfast in its commitment to advocating for policies that prioritise the well-being of liver patients. Throughout 2023, we actively engaged with policymakers, healthcare professionals, and stakeholders to influence positive change. By raising awareness of liver-related issues and

advocating for patient-centric policies, we strive to create an environment where liver patients receive the attention and care they deserve.

Scientific advancements are pivotal in improving the prognosis and quality of life for individuals affected by liver diseases. ELPA has fostered collaborations with the scientific community, contributing to cutting-edge research and innovative treatments. Our involvement ensures that the patient's voice is heard in shaping the future of liver healthcare.

As we navigate the complex landscape of liver health, ELPA remains committed to being a beacon of hope for patients, a force for positive change, and a catalyst for progress. The challenges may be great, but so is our determination to overcome them.

I extend my heartfelt gratitude to our members and partners for their unwavering support. Together, we will continue to make a lasting impact on the lives of those affected by liver diseases.

Together we are stronger!

Marko Korenjak

# ELPA Members in 2023



## **BELGIUM**

- Vlaams Hepatitis Contactpunt - VHC



## **FINLAND**

- The Finnish Kidney and Liver Association



## **BOSNIA & HERZEGOVINA**

- The Chronic Viral Hepatitis Patients Association, "B18"



## **FRANCE**

- SOS Hépatites Fédération



## **CROATIA**

- Croatian association for liver diseases, "Hepatos"
- HUHIV - Croatian Association for HIV and viral hepatitis



## **GEORGIA**

- Hepatitis C Cured Patient Association



## **CYPRUS**

- Cyprus Liver Patients Association, "Promitheas"



## **HUNGARY**

- Hungarian Association of Chronic Hepatitis Patients, "VIMOR"



## **DENMARK**

- Leverforeningen



## **IRELAND**

- Hepatitis C Partnership



## **EGYPT**

- Association of Liver Patients' Care – ALPC



## **ISRAEL**

- Israeli Association For The Health Of the Liver, "Hetz"

**NORTH MACEDONIA**

- Association for health education, prevention and better treatment - HEPTA
- Hepar Centar - Bitola

**NORWAY**

- proLAR

**POLAND**

- Star of Hope Foundation

**PORTUGAL**

- SOS Hépatites Portugal

**ROMANIA**

- Patients with hepatic impairment Association of Romania - APAH-RO

**RUSSIA**

- Humanitarian Action
- United Against Hepatitis

**SERBIA**

- Association for helping patients with chronic viral hepatitis, "HRONOS"

**SLOVAKIA**

- HEP HELP KLUB
- Šanca pre pečeň

**SLOVENIA**

- Association - SLOVENIJA HEP

**SPAIN**

- Catalan Association of Liver Patients - ASSCAT
- National Federation of Liver Patients and Transplanted – FNETH
- Spanish Patient Organization Lysosomal Acid Lipase Deficiency – AELALD

**SWEDEN**

- Riksföreningen Hepatit C – RHC

**TURKEY**

- Living with Hepatitis Association - HEPYAŞAM

**UNITED KINGDOM**

- British Liver Trust
- Hep C Positive
- Liver4Life





# **2023 HIGHLIGHTS**



## ISO QUALITY STANDARD CERTIFICATE 1<sup>st</sup> patients' association in Europe

ELPA is now the FIRST liver patient association in Europe with the official certification of the Quality Management System in place. ELPA managed to build a quality system of its work, was recognised by an external certification body and got the ISO 9001:2015 certificate related to its Management in Communication with Supporters and Stakeholders.

The purpose of ISO 9001:2015 is to help an organisation develop a robust Quality Management System to respond to evolving quality requirements in line with changing social, economic, and environmental expectations.

Implementing a Quality Management System in a nonprofit organisation like ELPA means:

- To rethink an organisation: why it exists; what are the priorities; how does it relate to its environment; how does it work; and what should be measured and improved.
- To develop a consistent way of working and monitoring thanks to the process approach and risk management.
- It serves internally to make deadlines and processes clear.
- To reinforce the message of clarity, trust, and professionalism towards supporters and donors.
- To enhance donors, supporters, beneficiaries, the general public, and stakeholders' satisfaction.



ELPA's work is reassessed each year, and 2023 marked the third year of the confirmation of the system. ELPA will continue improving its communication with Supporters and Stakeholders, showing its high level of professionalism and commitment towards liver patients.

# LIVER CANCER

## European Liver Screening Week

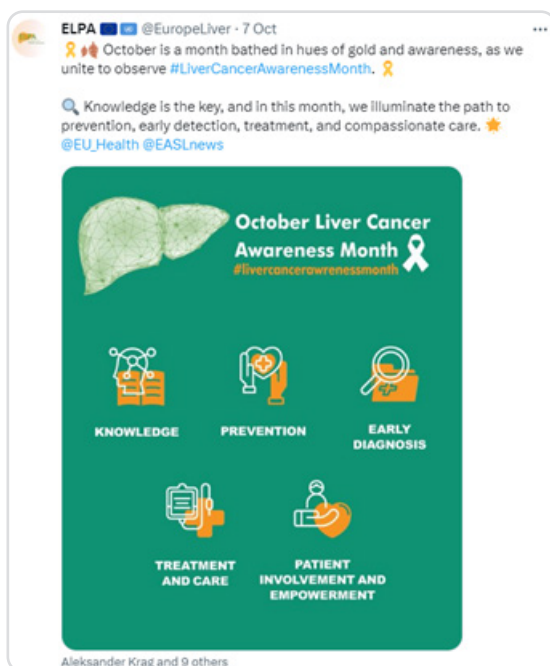
For 3 entire days, October 10-12, ELPA had a van in front of the European Parliament where it was possible to have the liver screened for free with a fast and non-invasive test. This was also the occasion to raise awareness of liver health because early detection is crucial in preventing liver diseases. More than 200 got screened and many more passed by the van to collect information.



## Liver Cancer Awareness Month– campaign and website

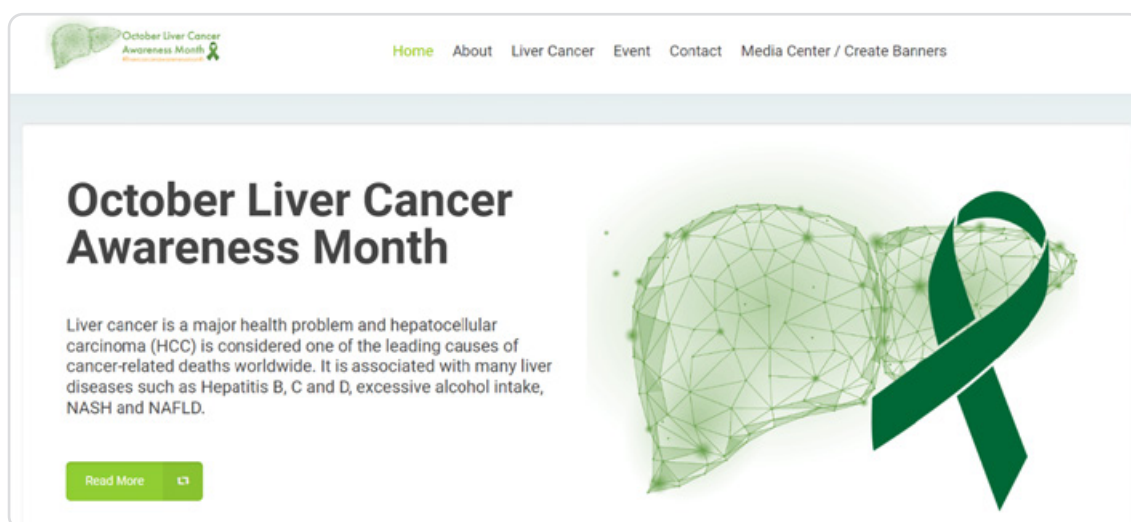
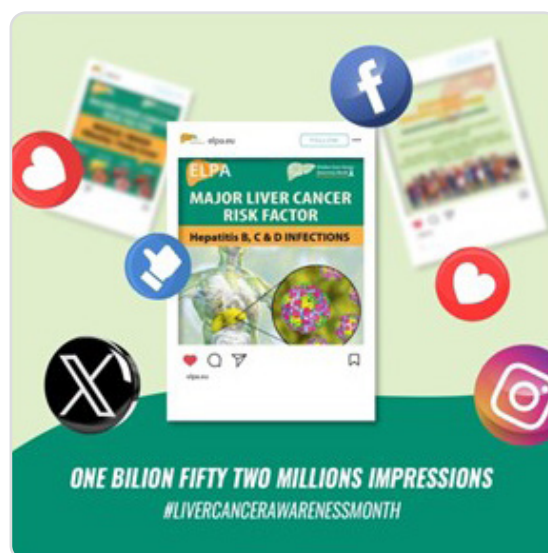
As every year, October brings liver cancer into focus to increase understanding of the disease, including its prevalence, approaches to screening and prevention, and treatment options. Liver Cancer Awareness Month (LCAM) is a great time to learn more about this vital organ's role and how to keep it healthy and raise awareness of the local and global impact among patients, family members, healthcare professionals, other stakeholders, and the general public. 2023 ELPA's social media campaign was based on the dissemination of updated and scientific information primarily focused on prevention since nobody is better than patients at informing other patients. This year, ELPA focused deeper on the importance of the correlation between liver cancer and obesity, alcohol consumption, hepatitis and cirrhosis. Part of the campaign was also dedicated to raising awareness among policymakers through some specific policy asks.

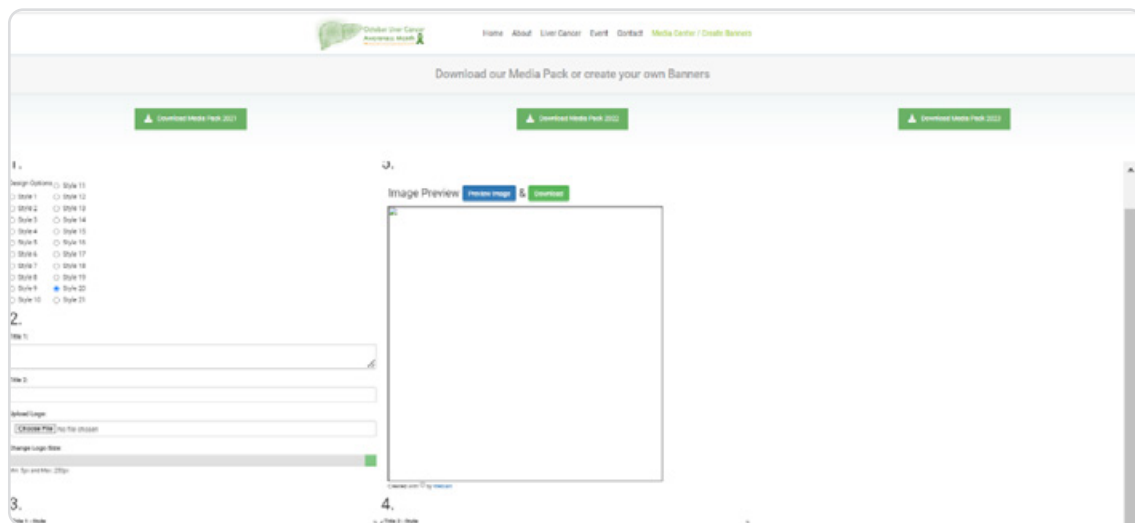




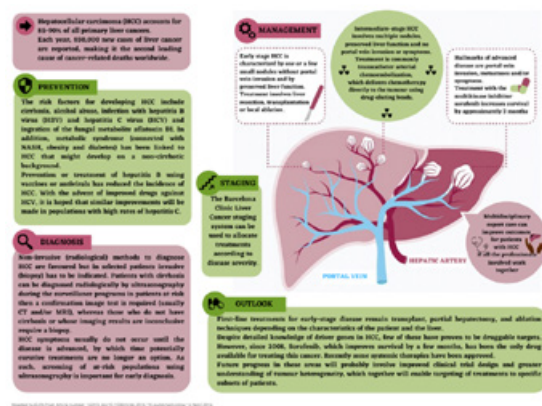
The campaign reached more than 1 billion impressions.

The website <https://livercancermonth.eu/>, which is entirely dedicated to liver cancer and was successfully inaugurated three years ago, allowed all ELPA friends to be involved in the campaign this year, too. Different banners, pictures and frameworks were available to download and personalise from the Media Centre to boost the dissemination of content in other contexts.





Besides raising an understanding of this challenging disease, the website also aimed at going beyond October 2023. A section was still dedicated to all the upcoming activities ELPA will organise in the field of education, awareness, and advocacy. And the part related to scientific info was refreshed and updated.



## Catalysing Change: Elevating Liver Health on the European Public Health Policy Agenda

ELPA organised a high-level policy event hosted by MEP Tomislav Sokol on October 12, 2023, in the European Parliament. The event brought together experts, policymakers, patients, and other stakeholders active in the field of liver cancer to explore what we can all do to ensure that no patient in Europe is left behind.

List of speakers:

- MEP **Tomislav Sokol**, EPP, Croatia.
- MEP **Ljudmila Novak**, EPP, Slovenia.
- **Marko Korenjak**, President of the European Liver Patients' Association (ELPA), Belgium.





- Dr. **Julianne Williams** PhD, Technical Officer Special Initiative for Innovation and NCDs (SNI), World Health Organization Regional Office for Europe.
- Prof. Dr. **Jordi Bruix**, MD, PhD, Advocacy leader, International Liver Cancer Association (ILCA), Spain.
- Prof. Dr. **Pierre Nahon**, MD, PhD, Hepatology Department, APHP Avicenne Hospital, France.
- Dr. **Isabel Graupera**, MD, PhD, Hepatologist Senior Specialist, Hospital Clinic of Barcelona, Spain.
- **Anca Toma**, Executive Director of the European Patients' Forum (EPF), Belgium.
- Dr. **Milka Sokolović**, PhD, General Director of the European Public Health Alliance (EPHA) Belgium.
- **Giacomo Donnini**, Program Director, Liver Health is Public Health, Global Liver Institute (GLI).
- **Lili Anna Gundelach**, Medical and Scientific Project Coordinator, Digestive Cancers Europe (DiCE) Belgium.

# FATTY LIVER

## European MASH Summit 2023. Fatty Liver, is this another pandemic? For a healthier future, for our children

On June 9, 2023, International Fatty Liver Day, ELPA organised a high-level event in the European Parliament to discuss Fatty Liver from different perspectives and to present a Manifesto and a Call to Action. The meeting started with a welcome speech and greetings by Mr Marko Korenjak, ELPA President, followed by the Member of the European Parliament, Mr **Loucas Fourlas**, Group of the European People's Party (Christian Democrats) from the Republic of Cyprus, addressing the topic from a political point of view.



After an introduction by Ms **Yiannoula Koulla**, leader of the ELPA Fatty Liver Working Group, there was a presentation by Prof Dr **Alexander Krag** M.D, EASL. He stressed how scientific & patient communities must fight side by side for young liver patients. Dr **Alessandro Gallina**, PhD, EPHA, presented the impact of prevention programmes on public health in the EU. **Elena Balestra**, EPF, gave an overview of tackling the challenge of chronic disease from the patient's perspective. Prof Dr **Sven Franque** M.D, Antwerp University, pointed out how NAFLD is highly prevalent in children, and

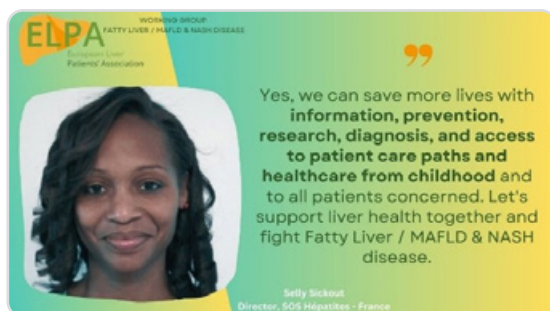
overweight/obesity is a major risk factor. **Donna Cryer**, GLI, showed how only a global effort can reduce the burden of liver disease. Dr **Andreea Ciudin** M.D, El Vall d'Hebron Barcelona Hospital, pointed out that in the WHO Europe region, less than half (43%) of the children consume fresh fruit daily. Primary prevention and management of obesity are essential components. If we succeed, this response can reduce not only overweight and obesity levels but also the burden of non-communicable diseases. **Alexandru Popovici**, EuropeActive, stressed how healthy lifestyle and prevention education must be part of school programmes. And presented two examples of Erasmus+ programmes: HEPA and EUMove project. Prof Dr **Bart Koot** M.D, ESPGHAN, listed what is needed to effectively detect and treat children with NASH: improvement in tools to detect NAFLD/advanced NAFLD, more knowledge of natural history, more knowledge of risk factors for the complicated course, cost-effectiveness studies, improvement in treatment: lifestyle-drugs, awareness among health care workers, and prevention. Before the closing remarks by Mr Marko Korenjak, ELPA President, a Manifesto and a Call to Action was presented with the commitment to define, in the near future, concrete action for each of the 6 points stressed in the document.



## Fatty Liver Month, ELPA Campaign

The European Liver Patients Association (ELPA), in close collaboration with the ELPA Fatty Liver Working Group, organised the social media campaign #FattyLiverMonth. Run in June 2023, it had its highest expression on International NASH Day on June 9, 2023, in the high-level Summit organised in the European Parliament.

The campaign revolved around different messages. Some informed about the diseases. Some reminded patients, partners, experts, policy decision-makers, stakeholders, and the general audience that Fatty Liver is our next most significant challenge in Europe as its rate among the population is increasing. It is a priority to push forward the discussion about these diseases and promote better and more comprehensive communication on this topic. In particular, the campaign focused on prevention and explored solutions contributing to tackling Fatty Liver. As there is still no treatment, the best way of dealing with the condition is for the patient to implement lifestyle changes, giving up to unhealthy diet and sedentary culture. This year, the campaign wanted to focus again also on the name change, stressing how important this is for the liver patients' community. In addition, part of the campaign was dedicated to stress messages coming from all the stakeholders. A series of statements by the members of the ELPA Fatty Liver working group was posted for a week, followed by videos realised by ELPA involving doctors and experts.





*ELPA Clinical Trials Programme, Group Picture*

## ELPA Clinical Trials Programme 2023

For its members, ELPA organised the second edition of the ELPA Clinical Programme 2023 - Building Patient Experts. The programme aims to improve patient centricity by training patient experts. The areas of interest are MASH and MASLD, which are increasingly important. It is a peer-to-peer training course in which some EUPATI fellows and some topic experts from ELPA members will be the trainers. In 2023, the first part was held in Vienna, and the second part was held in Valletta, where ELPA also organised a meeting with a representative of the Malta Medicines Authority and an EMA PRAC member to explain the patient-reported ADRs systems.

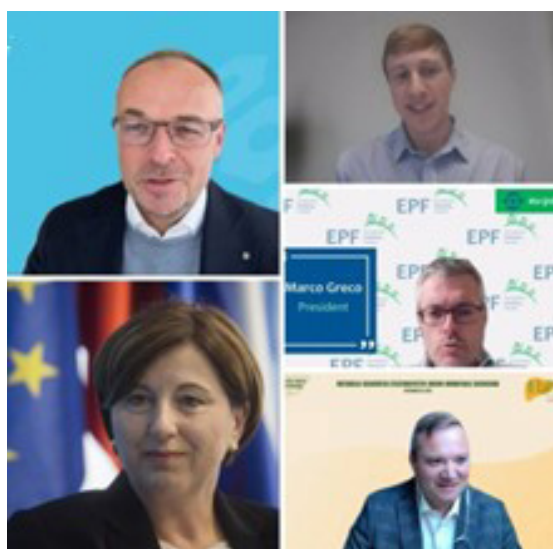


*ELPA Clinical Trials Programme, Group Picture*

## Metabolic-associated steatohepatitis (MASH), ELPA Roundtable discussion

This roundtable discussion was organised by ELPA in the framework of the 'liver diseases as a part of public health policies let's talk series'. The series aims at answering two questions: How can we place liver health higher in the European public health policy agenda? How should long-term and





comprehensive public policies be structured.? Moderated by ELPA President **Marko Korenjak**, this episode focused on MASH and had among the speakers **Ljudmila Novak**, MEP, EPP, Dr. **Marco Greco** PhD, President of European Patient Forum (EPF), Dr. **Alessandro Gallina** PhD, Policy Manager for NCD Prevention, European Public Health Alliance (EPHA), Prof. Dr. **Alexander Krag** M.D, Secretary General, European Association for the Study of the Liver (EASL). Speakers explored obstacles and solutions to place liver health higher in the European public health policy agenda, structure long-term and comprehensive public policies to tackle the commercial determinants of health, raise awareness about primary prevention and education and fight health inequities and inequalities across Europe.

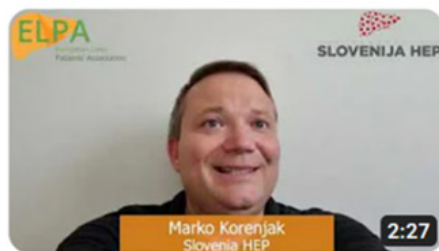
# HEPATITIS

## World Hepatitis Day campaign

In July 2023, the European Liver Patients Association (ELPA) organised a monthly social media campaign focused on Hepatitis. Run during the entire month; it had its highest expression on World Hepatitis Day on July 28, 2023. The campaign revolved around different messages. Some informed about the different types of Viral Hepatitis. Some reminded patients, partners, experts, policy decision-makers, stakeholders, and the general audience that Viral Hepatitis is still a significant challenge in Europe, and it is a priority to push forward the discussion about its elimination and promote better and more comprehensive communication on this topic. In particular, the campaign focused on prevention and explored solutions contributing to tackling mainly Hepatitis B, D and C. This year, the campaign



wanted to involve ELPA members more than ever. , ELPA collected videos from its members stating the importance of Hepatitis elimination in their counties. The series of video statements by the ELPA members was shared on ELPA social media profiles during the last week of the campaign to strengthen the message approaching World Hepatitis Day on July 28, 2023.



#WHD-Marko Korenjak-Slovenia  
HEP Elpa Member



#WHD-Ivana Sabova-Sansa pre  
preceen Slovakia Elpa Member



#WHD-Hilal Unalmis Duda-ELPA  
Member Living with Hepatitis



Dr.Teresa Casanovas-ELPA member  
ASSCAT Spain



#WHD-German Corbacho-FNTECH  
Spain Elpa Member



#WHD-Julio Burman-Hetzliver Israel  
Elpa Member



youtube.com  
#WHD-Josip Kresovic HUHIV Croatia



#WHD-Yiannoula Koulla-President  
of Cyprus Liver Patients Association

# RARE LIVER DISEASES

## Driving EU policy change for people living with rare diseases: a focus on Wilson's disease

On February 28, 2023, Rare Disease Day, the European Liver Patients' Association and the Wilson's Disease Policy Network brought together key experts and stakeholders in Wilson's disease, rare diseases and health policy. A range of speakers drew on the experiences of people living with Wilson's disease to discuss how gaps in care and policy barriers can impact health outcomes and quality of life. They also discussed key activities and initiatives at the EU level and explained the priority policy actions that are urgently needed to improve the lives of people living with rare conditions. The event also marked the launch of the Policy brief on Wilson's disease that was developed by the members of the multidisciplinary Wilson's Disease Policy Network. The event was hosted in Brussels by MEP **Ljudmila Novak**, who welcomed all the participants and gave an introductory overview of the importance of raising awareness about rare diseases and,

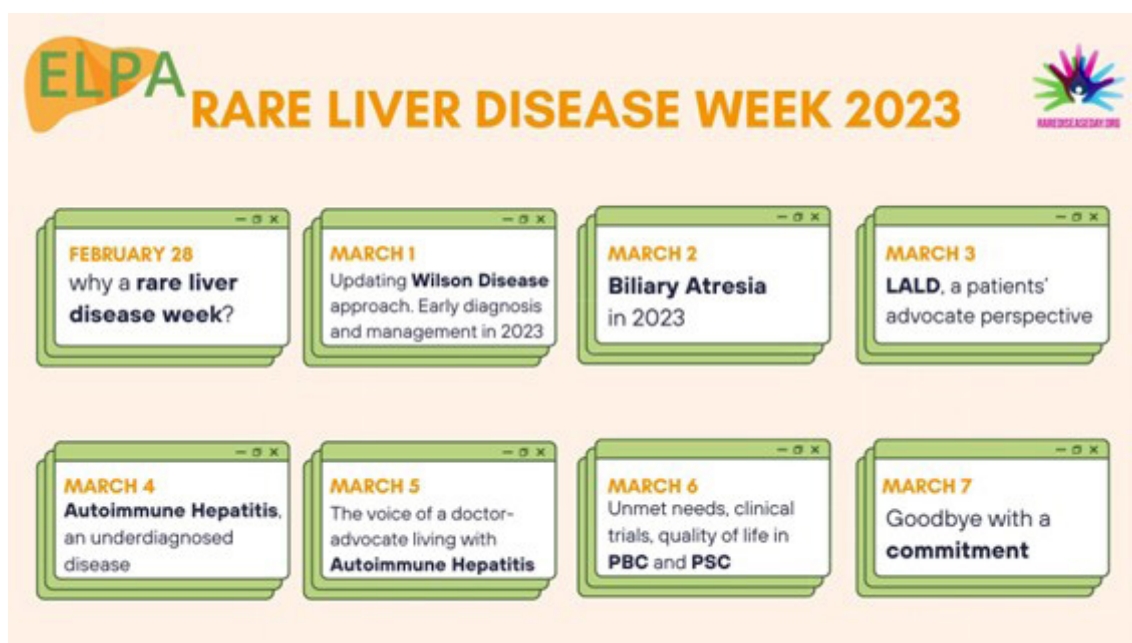


*Sindee Weinbaum, Leader of the ELPA working group on rare liver diseases*

in particular, about a rare liver disease such as Wilson's Disease. Sindee Weinbaum, the Leader of the European Liver Patients' Association working group on rare liver diseases, took the floor and described the aim of the meeting and the role of Wilson's disease Policy Network. Two patients' testimonies followed the introduction. The first was by **David Martín Miguel** from the Asociación Española de Familiares y Enfermos de Wilson (Spanish Association for Wilson's Disease Patients and Their Relatives). The second was by **Caroline Roatta**, from the Association Bernard Pépin in France. Both stressed the patient perspective and the role of patients in improving Wilson's disease health outcome. **Karl Heinz Weiss**, Associate Professor of Gastroenterology from the Salem Medical Center in Germany, analysed the barriers to best-practice care for people living with Wilson's disease. An insight into EU action on rare diseases with a focus on rare disease research was given by **Hélène Le Borgne**, representing the European Commission, Directorate-General for Research and Innovation. The event was wrapped up by a panel discussion moderated by **Jody**

**Tate** from the Wilson's Disease Policy Network. **Marko Korenjak**, President of the European Liver Patients' Association, **Alexander Natz**, Secretary-General of the European Confederation of Pharmaceutical Entrepreneurs and **Alina Senn** representing the European Commission, Directorate-General for Health and Food Safety, joined Karl Heinz Weiss and David Martín Miguel to discuss priorities and actions to drive changes in rare disease policy at the EU level. MEP Ljudmila Novak addressed her closing remarks to all the participants stressing the importance of collaboration among stakeholders to close the gaps in care and overcome policy barriers for Wilson's disease patients.

## ELPA rare liver diseases week



In 2023 ELPA celebrated, as every year, Rare Disease Day on February 28. However, ELPA decided to build a one-week campaign focusing on Rare Liver Diseases. It started with a message from the Leader of the ELPA Working Group on Rare Liver Disease. Then, it continued tackling a different liver disease every day from different angles. ELPA collected contributions from the medical scientific community but also patients, patients' family members, and patient advocates. Videos were done in the form of lectures or interviews.



## International PBC Day 2023

ELPA was honoured to celebrate International PBC Day on September 13, 2023. ELPA's social media campaign has been a great occasion to raise awareness on primary biliary cholangitis (PBC) among the decision-makers, engage patients, clinicians, and policymakers, push forward the discussion about this disease, and promote better and more comprehensive communication on this topic. In particular, ELPA's campaign focused on how too many liver disease patients fall victim to the unknown. For many liver diseases, their causes and effective diagnostics, treatments and cures remain unclear, which is the reality of rare liver diseases like primary biliary cholangitis (PBC), however, ELPA shared hope and reasons for optimism.



## Global PSC Awareness Day - campaign and webinar

Primary Sclerosing Cholangitis (PSC) knows no boundaries. It is a rare, immune-mediated liver disease that affects the bile ducts and liver. On October 29, 2023, Global PSC Awareness Day, ELPA organised a social media campaign and partnered with different patient organisations to bring you a webinar with experts from around the world.





## MORE AND MORE

### Meet the principal Investigators!

In 2023 ELPA continued to team up with some of the Principal Investigators involved in the IPcureB and project, releasing a new video revolving around the scope and the content of the project. Videos can be watched on the ELPA YouTube channels and on the projects' websites.



## Celebrating World Liver Day

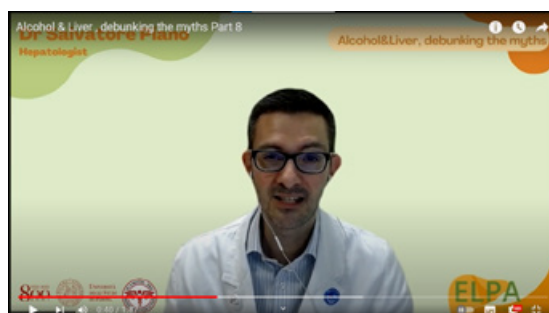


## ELPA is now member of



## Alcohol & Liver, debunking the myths. The 2023 ELPA campaign for alcohol awareness

In 2023 ELPA reshared this special campaign to inform about alcohol-related harm made of short videos featuring Dr **Salvatore Piano**, M.D., busting some common perceptions about alcohol and liver.



## ELPA Members Project Support 2023

After the success of the 2021 and 2022 editions, in 2022, ELPA worked even closer with its members on projects developed at the national level.

In 2023, ELPA supported the projects of 20 associations in 15 different countries:

**Bosnia&Herzegovina, Cyprus, Egypt, Finland, France, Israel, North Macedonia, Romania, Serbia, Slovenia, Slovakia, Spain, Sweden, Turkey, United Kingdom.**



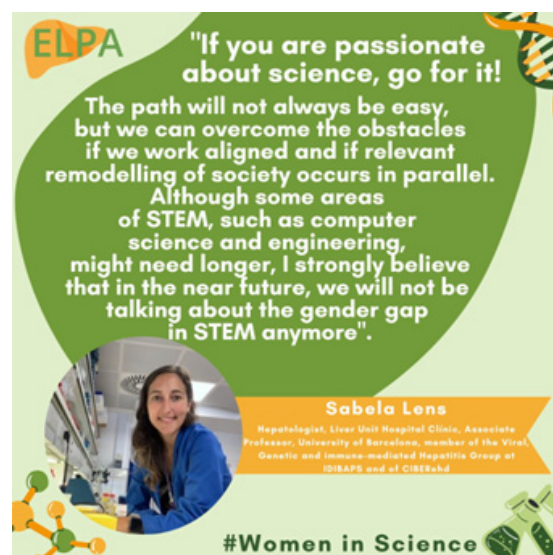


## International Day of Women and Girls in Science and International Women's day

On March 8, 2023, ELPA celebrated, as every year, International Women's Day, and as every year, with the pleasure of talking with powerful and inspiring women. This year we published two interviews. The first one featured Dr **Su Wang**, who gave us a very interesting testimony of her personal and professional life as a doctor, a patient, and a mother. In the second one, in a powerful and inspiring talk, **Irmí Gallmeier** discussed the relationship between Pharma & patients with ELPA.



On February 11, 2023, ELPA celebrated the International Day of Women and Girls in Science, supporting some statements on this topic by doctors collaborating with ELPA.





# **POLICY AND ADVOCACY ACTIVITIES**



# Focus on European Health Policy

## ETF meeting on vaccines and therapeutics against COVID-19

On January 12, 2023, ELPA President participated in an ETF meeting in the framework of the European Medicine Agency (EMA). The Emergency Task Force (ETF) is an advisory and support body that handles regulatory activities in preparation for and during a public health emergency, such as a pandemic. The ETF is responsible for the following activities:

- Providing scientific advice to developers of medicines that could address the public health emergency.
- Reviewing scientific data on these medicines, including data requested from their developers.
- Engaging in preliminary discussions with these developers and providing them with feedback on how to develop their medicines best.
- Offering scientific support to facilitate clinical trials in the EU for the most promising medicines.
- Supporting the work of EMA's scientific committees evaluating applications for authorisation of these medicines and monitoring their safety.
- Providing scientific recommendations on the use of medicines before their authorisation, in liaison with EMA's scientific committees, working parties and scientific advisory groups. These medicines can include medicines already authorised for a different indication.
- Making the best use of real-world evidence to support preparation for crises and responding to them. This includes evidence from healthcare databases across the EU via DARWIN EU.
- Cooperating closely with stakeholders and with European and international organisations.

## Virtual Meeting on Informed and Shared Decision-Making

The European Cancer Organisation organised a Virtual Meeting on Informed and Shared Decision-Making on January 18, 2023. ELPA representative was ELPA Vice President Ivana Dragojević, who sits on the Patient Advisory Committee of the European Cancer Organisation. The meeting highlighted the importance of achieving more well-informed and shared decision-making with cancer patients in routine oncology care. Best practice tools to help achieve this were presented alongside the most recent research on the topic. Expert speakers from the patient and healthcare professional perspective discussed challenges to achieving informed and shared decision-making and recommendations for overcoming these. The meeting was held in conjunction with the publication of a new open-access article in the Journal of Cancer Policy, "Cancer literacy – Informing patients and implementing shared decision-making".

## 72<sup>nd</sup> ECDC Advisory Forum meeting

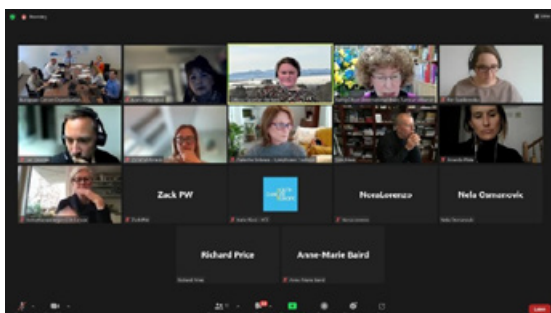
As part of the European Centre for Disease Prevention and Control - ECDC Advisory Forum, ELPA President Marko Korenjak joined the 72<sup>nd</sup> meeting on February 21-22, 2023. The Advisory Forum is composed of senior representatives of national public health institutes and agencies, nominated by the member states on the basis of their scientific competence, and a public health official from the European Commission. The European scientific associations and civil society groups also send observers to the Advisory Forum. The ECDC Director invites WHO to attend the meetings to ensure synergy. As well as supporting ECDC's scientific work, the Advisory Forum is also a mechanism for exchanging information, pooling health knowledge and furthering public health cooperation.



*Marko Korenjak, ELPA President - Dr Andrea Ammon, MD, MPH, ECDC Director, 72nd ECDC Advisory Forum meeting*

## Patient Advisory Committee of the European Cancer Organisation meeting

On February 22, 2023, ELPA Vice-President Ivana Dragojević participated as a member in a meeting of the Patient Advisory Committee (PAC) of the European Cancer Organisation. Patient advocates are at the heart of the European Cancer Organisation, with 22 patient advocacy groups involved in policy-making and activities. The Patient Advisory Committee, established in 2008, provides European patient organisations and bodies involved in patient care with a solid platform to express their expectations in solidarity with Member Societies and provides the European Cancer Organisation with direct insight into the issues and challenges faced by cancer patients.



## Addressing the unmet medical needs of people living with a rare disease: What will it take?

On World Rare Disease Day 2023 (March 1, 2023), the global multistakeholder policy initiative Partnering4PNH organized the event "Addressing the unmet medical needs of people living with a rare disease: What will it take?" taking place at the European Parliament and attended by some ELPA representatives. During the event, a multidisciplinary panel of experts from the rare disease community discussed how the EU and other countries could continue to play a central role in the rare disease space by stimulating research and

innovation, developing new therapies, and ensuring patient access. We stand at a crossroads in setting new standards for people living with a rare disease. Speakers included:

MEP **István Ujhelyi**

MEP **Stelios Kypouropoulos**

Dr **Morag Griffin**, Haematologist PNH Specialist, Leeds Teaching Hospital, United Kingdom

**Louise Arnold**, PNH Specialist Nurse, Leeds Teaching Hospital, United Kingdom

**Alexander Natz**, Secretary General, EUCOPE



## Event on the European Health Data Space

As a co-rapporteur of the European Health Data Space file in the ENVI Committee, MEP Tomislav Sokol has decided to host an event on the EHDS topic at the European Parliament on February 28, 2023. ELPA representatives attended the meeting that brought together the essential stakeholders to discuss this revolutionary proposal. The European Health Data Space is a health-specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework that aims at empowering individuals through increased digital access to and control of their electronic personal health data at the national level and EU-wide, and support to their free movement, as well as fostering a genuine single market for electronic health record systems, relevant medical devices and high-risk AI systems, providing a consistent, trustworthy, and efficient set-up for using health data for research, innovation, policy-making and regulatory activities.

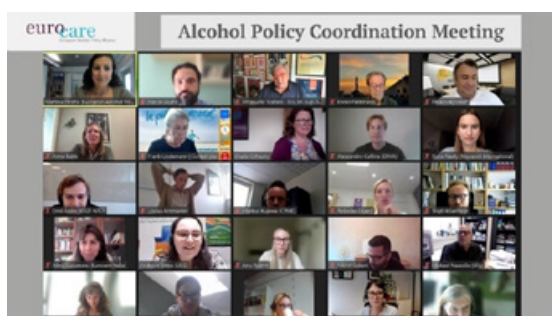


## ECDC HBV-HCV network meeting

**ELPA Vice-President Tove Frisch attended the ECDC conference** as a representative of ELPA in Stockholm on March 14-15, 2023. The conference was divided into six different sessions. On the first day, participants listened to an overview of the hepatitis B and C situation in the EU/EEA moderated by **Karl Ekdahl**. **Karin Tegmark Wisell**, Director General of the Public Health Authorities in Sweden, talked about the situation in the country, as did **Martin Kåberg**, a medical doctor from Karolinska. The second section, moderated by Teymur Noori, was dedicated to the topic of achieving hepatitis B and C elimination in the EU/EEA. **Katie Turpie** from the National AIDS Trust talked about how far we can get by monitoring viral hepatitis in the EU and what the pitfalls might be. **Thomas Seyler** (Eur Mon Cen for Drugs and Drug Addiction) talked about the relationship between PWIDs and hepatitis C. **Liudmila Mosina**, WHO Europe, talked about the struggle to control the hepatitis B situation in Europe. At the end of session 2, the ELPA representative joined a panel discussion of key stakeholders to explore elimination priorities. Section 3 was dedicated to exploring how to improve the information for action focusing on hepatitis C with **Erika Duffell** as moderator. **Odette Popovici** from Romania talked about the gaps to fill in her country and about the 'Sphere-C-project'. **Benjamin Bluemel** talked about the gaps in data, like multiple data sources and better estimation of the hep C prevalence. **Georgios Nikolopoulos**, Cyprus, and **Aiden McCormich**, Ireland, took part with the others mentioned above in a panel discussion about what steps to take for better measurements of hepatitis C. **Marieke van der Werf** moderated the fourth session about reducing the undiagnosed population of hepatitis B and C. Regarding barriers to testing and key actions, **Marcelo Naveira**, WHO Europe, talked about self-testing and what to do if you get a positive result. **Janelle Sandberg**, ECDC, talked about barriers to testing and the situation in the EU. Session 5 focused on elimination in vulnerable populations, and it was moderated by **Otilia Mardh** and Thomas Seyler. **Sigurdur Olafsson** showed the successes and the challenges of the efforts to eliminate hepatitis C among people injecting drugs in Iceland. Apart from drug users, the prisons were also covered by Thomas Seyler and Erika Duffell. Future priorities for the hepatitis response across the EU/EEA, moderated by Erika Duffell and **Anastasia Pharis**, were the title of the last session. A session that looked forward towards surveillance, prevention and control of hepatitis B and C but also towards the near future, what to do next.

## EUROCARE policy meetings

As a Eurocare member, ELPA took part in all the EURO CARE policy meetings to discuss the future association's steps in the field of advocacy monthly organised. Eurocare is an alliance of non-governmental and public health organisations across Europe advocating for the prevention and reduction of alcohol-



related harm. Member organisations are involved in advocacy and research, providing information and training on alcohol issues and services for people whose lives are affected by alcohol problems. EURO CARE's mission is to promote policies that prevent and reduce alcohol-related harm.

## HERA Civil Society Forum Meetings

Being Part of the HERA Civil Society Forum, some ELPA representatives participated in all the CSF group meetings. The work of CSF is organised in three working groups, and ELPA is involved in Working Group 1:

### Working Group 1 – Future of HERA

### Working Group 2 – Identified health threats (AMR, pathogens with high pandemic potential, CBRN threats)

### Working Group 3 – Training programme and information

Working group 1 also drafted a discussion paper in which the HERA Civil Society Forum recommends stronger investment in health emergency preparedness and response capacities.

In 2022, ELPA was appointed as a member of the HERA Civil Society Advisory Forum. The Advisory Forum is the highest body in HERA for discussing the strategic focus and setting tactical goals with high-level management. The Health Emergency Preparedness and Response (HERA) department aims to prevent, detect, and rapidly respond to health emergencies. HERA, created in the aftermath of the COVID-19 pandemic, will anticipate threats and potential health crises through intelligence gathering and building the necessary response capacities.



*HERA Civil Society Forum Meeting, group picture*

## MEP friends of the liver group call to action ‘the EU must lead on viral hepatitis elimination by 2030

The Live Webinar took place online on April 25, 2023. On 25 October 2022, the MEP Friends of the Liver Group hosted an event titled ‘The final push to eliminate viral hepatitis how can the EU lead the successful achievement of this global public health priority?’ in the European Parliament. The European Association for the Study of the Liver (EASL) and the ACHIEVE Coalition supported the event. Whilst a lot has been achieved with the recognition of viral hepatitis B and C in Europe’s Beating Cancer Plan and EU4Health funding, it is equally clear that a lot must. It can be done to ensure that the EU collectively meets the WHO’s 2030 elimination deadline and also makes a significant contribution to ensure that viral hepatitis is eliminated in the EU neighbourhood and globally, supporting low-income countries. A Call to Action for the EU, European Commission, and EU Member States to lead on viral hepatitis elimination by 2030 was put together with the insight generated during the event, which several MEP Friends of the Liver Group Members have endorsed. This webinar, attended by ELPA Vice-President Ivana Dragojević, aimed at presenting the MEP Friends of the Liver Call to Action’s key objectives and receiving feedback from participants on how to turn them into actionable initiatives.

## The European Semester: a tool to embed health, equity, and well-being across the EU

EuroHealthNet organised a stakeholder roundtable with the objective of exchanging perspectives on the potential of strengthening health, equity, and well-being in the European Semester. Hosted by MEP **István Ujhelyi**, policymakers, national experts, and EU stakeholders participated actively in the event. National public experts (health, social affairs, etc.) from EuroHealthNet’s partnership, European Commission officials, Permanent Representations and other vital EU stakeholders were invited to the meeting. As Europe deals with the aftermath of the pandemic, the ongoing climate crisis, global conflicts, larger demographic changes



and the technological revolution, the wellbeing of our societies is threatened. At EU level, the European Semester is a key macro-economic process that can be used to help Member States to mitigate these crises through investments and reforms, while promoting health, equity and wellbeing. EuroHealthNet has been analysing the European Semester process from a health equity and wellbeing perspective since its inception in 2011 - determining whether its outcomes have resulted in more equitable, resilient,

'better' societies, and how. The approach taken by EuroHealthNet also means exploring how the European Semester process can contribute to reforms in other key areas important to health and wellbeing, like housing, early childhood development and care, social inclusion via skill building and literacy, the digital transition and climate adaptation as well as food system sustainability.

## Bridging the gaps, a Pan-European study on digestive diseases across Europe

On April 26, 2023 United European Gastroenterology organised an event at the European Parliament that brought together digestive health experts and key stakeholders from the European health community for a lively and solution-oriented discussion on the current state of digestive health across Europe. On this occasion, UEG also launched their latest publication on the burden of digestive diseases. Based on the key findings, they have issued an Open letter addressed to EU leadership with six policy recommendations to create a stronger policy environment for digestive health in the EU.



## Advanced Therapy Medicinal Products in Europe: combining sustainability, innovation and respect for patients' rights

Also this year, Active Citizenship Network celebrated the European Patients' Rights Day - which has reached its 17<sup>th</sup> edition - with a conference hosted by MEP **Brando Benifei** (S&D) and organised with the support of the MEPs Interest Group "European Patients' Rights & Cross-Border Healthcare" and the TRANSFORM



MEP Interest Group. The 2023 conference represented the first in-person European celebration of the European Patients' Rights Day since the beginning of the Covid-19 pandemic. From the research towards a growing number of ATMPs to their use once approved, the unifying themes seem to be essentially the following: sustainability, innovation, equity. To these, two further elements must be added, which should also be taken into account as drivers in choices having to do with ATMPs: respect for and reinforcement of patients' rights. It is no coincidence that the issue of Advanced Therapy Medicinal Products is related to several rights set out in the European Charter of Patients' Rights, which is at the heart of the EPRD celebrations.

## Conference on Clinical Trials in Cirrhosis in Relation to NASH

The conference was held at the Vall d'Hebrón University Hospital in Barcelona, on April 28, 2022, and was attended by Dr Teresa Casanovas, ELPA Scientific Committee Leader. Liver disease due to the accumulation of fat in the liver and its metabolic complications such as diabetes, hypertension, increased triglycerides and cholesterol in the blood, etc., can be severe, it is closely linked to obesity, and its prevalence is increasing globally. It is also known that there is a subgroup of these patients with risk factors that will progress to cirrhosis and with more accelerated decompensation. The lectures presented covered various aspects of clinical trials being conducted in patients who have advanced fibrosis or cirrhosis of the liver as a result of fatty storage disease and who have not yet decompensated. The studies that are being carried out are progressing slowly and are highly complex in this group of patients. However, it is hoped to stop the evolution or even reverse the liver alterations in some milder cases. With these objectives, the conference program covered various aspects of international clinical trials in patients with advanced fibrosis/cirrhosis due to NASH and the current difficulties. As an association of liver patients, we ask ourselves, what should the role of patient associations be in relation to clinical trials in NASH disease? It is evident that a lot of information and dissemination is required so that medical-health teams and social networks become more involved and that the patients themselves feel more empowered and responsible for decisions about their health.

## ESPGHAN Annual Meeting

ELPA representatives attended the ESPGHAN Annual Meeting on May 17-20, 2023, in Vienna. The 55<sup>th</sup> Annual Meeting of the European Society for Paediatric Gastroenterology, Hepatology and Nutrition was at the forefront of education provision and knowledge exchange of innovative treatments and research discoveries to enhance the standards of care for patients and help paediatric gastroenterology, hepatology and nutrition professionals, improve their practice. The European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) is a multi-professional organisation whose aim is to promote the health of children with special attention to the



*Marko Korenjak, ELPA President - Prof Dr Ulrich Baumann M.D., ESPGHAN President - Julio Burman, ELPA Vice President, ESPGHAN Annual Meeting*

gastrointestinal tract, liver and nutritional status, through knowledge creation, the dissemination of science-based information, the promotion of best practice in the delivery of care and the provision of high-quality education for paediatric gastroenterology, hepatology and nutrition professionals in Europe and beyond.

## INFARMED meeting



*Dr Carlos Alves M.D, Vice President of the Executive Board INFARMED - Dr Érica Viegas Pharm.D., member of the Executive Board INFARMED - Marko Korenjak, ELPA President, Dr Márcia Silva Pharm.D., Head of the PhV department - INFARMED meeting*

ELPA President Marko Korenjak participated in a round table discussion organised by INFARMED in Porto on May 30, 2023. INFARMED is a Portuguese Government agency accountable to the Health Ministry that evaluates, authorises, regulates and controls human medicines as well as health products, namely, medical devices and cosmetics, for the protection of Public Health. The Institute's main goal is to ensure the quality, safety and efficacy of medicines and the quality, safety and performance of health products in order to avoid the risks of their use while ensuring adequate standards of public health and consumer protection. The debate focused on how to involve patients in the healthcare regulatory system in Portugal and beyond.

## Innovations in NAFLD Care Workshop 2023

Dr Teresa Casanovas, ELPA Director and Scientific Committee Leader and Yiannoula Koulla, leader of the ELPA Working Group on Fatty Liver, participated in the Innovations in NAFLD Care Workshop on May 26 and 27, 2023. Ms Koulla gave a presentation describing the care pathways of a liver patient during a lively session dedicated to patients' organisations. The workshop was the third meeting in the Innovations in NAFLD Care Series, and it provided a platform bringing together the relevant stakeholders and patients to optimize NAFLD care. The 2-day program explored the different perspectives that healthcare professionals and patients with NAFLD daily face. It highlighted where healthcare providers and policy-makers can implement the most comprehensive models of NAFLD care.



*Dr Teresa Casanovas M.D., ELPA Scientific Committee Leader and ELPA Director - Yiannoula Koulla, Leader of the ELPA working group on fatty liver, Innovations in NAFLD Care Workshop*

## EMA webinar on the revision of the pharmaceutical legislation

On June 16, 2023, ELPA Vice President Tove Frisch attended the webinar on the revision of the new EU pharmaceutical legislation organised by the European Medicine Agency (EMA). The EU pharmaceutical reform was presented for patients, users, healthcare professionals. Speakers explained the background to the reform: to give patients what they need but also support the industry in its finding/producing new and better medicines. They also stressed what would be the future of the reform: all medicines should come to the patients, authorisations and labelling must be simplified, and strong incentives for access to medicines have to appear. A strategy for public emergencies was also stressed, taking into account coordination, monitoring-management and shortage prevention plans considering a Union list of critical medicines. Also, the 3 As around which the reform revolves were presented: Access, Availability, and Affordability.

## EU4health stakeholders' conference

On June 9, 2023, the European Commission hosted the Stakeholders' Conference in Brussels and online. The event focused on important health priorities and offered an opportunity to reflect on priorities, strategic orientations, and future work programs.

The event programme consisted of sessions on five topics:

- Improving and fostering health.
- Protecting people.
- Enhancing access to medicinal products and medical devices.
- Preparing health systems for the digital era.
- Exploring synergies and complementarities.



The Conference also was the occasion to hear about the first analysis of the outcomes of the Stakeholders' Targeted Consultation on EU4Health. ELPA representatives had the possibility to interact with a wide range of stakeholders, including organisations representing patients, civil society, and other parties active in public health and social issues; health professionals and healthcare providers; researchers, academia, and experts' networks; businesses and their associations; and Member States authorities.

## 4<sup>th</sup> Patient Centricity and Collaboration World Congress 2023 Europe

Taking place on June 1 and 2, 2023, the meeting aimed at building meaningful collaborations among industry, advocacy groups, clinicians, researchers, and most importantly, patients and their caregivers. The ultimate goal was to gain practical strategies and best practices on challenges, innovations, technologies, and concepts. ELPA Vice President Ivana Dragojević was among the speakers and presented ELPA and the role of patients' organisations in a multistakeholder environment. She also challenged the concept of patient centricity versus patient engagement, and she gave some examples of patients' advocacy activities.



## Europe's Tomorrow: Vaccination and Prevention Summit



On June 28, 2023, ELPA representatives attended the first Summit about vaccination and prevention organised by ThinkYoung. The meeting was an opportunity for policymakers, health experts, young people, start-ups, and civil society organisations to come together and discuss the challenges in the area of vaccinations and prevention both at the European and Member State levels. The Summit also aimed at spotlighting youth voices concerning vaccines and prevention, connecting the views of young people with high-level stakeholders in the healthcare industry and related policy fields. The Summit consisted of a series of panel discussions and also hosted an exhibition space for start-ups that work on vaccination and prevention.

## Is the EU facilitating an industrial epidemic?

On June 27, 2023, ELPA representatives attended the meeting organised by the European Alcohol Policy Alliance - Eurocare at the European Parliament. The conference highlighted the powerful, cutting-edge concept of commercial determinants of health while setting out its position on alcohol labelling. Alcohol is among the biggest commercial determinants of health, alongside tobacco, ultra-processed food and fossil fuel. The panel featured presentations from the foremost figures in the field, such as Dr **Nason Maani**, Lecturer in Inequalities and Global Health Policy at the University of Edinburgh and Professor **Anna Gilmore**, Professor of Public Health, Director of the Tobacco Control Research Group at the University of Bath. These presentations were followed by discussions of the topic by policymakers and MEPs, as well as

other highly influential stakeholders. Eurocare also launched its position paper on alcohol labelling. The Position paper contains the following recommendations to the European Commission:

- Release the proposal promised by the end of 2022 for an EU mandatory alcohol labelling (with nutritional and ingredient information ON LABEL like all other food and drink products sold to consumers).
- Adopt alcohol health warnings supported by the establishment of an EU health warnings library.



*“An open letter, signed by 68 leading civil society organisations, was sent to the President of the European Commission. The letter is asking the European Commission to release the alcohol labelling proposal as soon as possible, to stop being influenced by economic operators and to stand up to EU citizens’ right to basic alcohol health information,”* said **Florence Berteletti**, Secretary General of Eurocare.

## Supporting Civil Society Organisations: ways to sustainable funding

On June 26, 2023, the EU4Health Civil Society Alliance, of which ELPA is a member, organised an event at the European Parliament to discuss EU funding mechanisms to support EU Civil Society Organisations (CSOs). Some ELPA representatives attended the meeting hosted by MEP István Ujhelyi and stressed the State of play on funding for CSOs at the European level and ways forward to guarantee sustainable funding for CSOs from all sectors. Participants discussed ways of mainstreaming frameworks at the EU level that would allow for sustainable funding of civil society across sectors. As outlined in the 2022 European Commission’s Rule of Law Report and the European Civic Forum report, Civil Society Organisations (CSOs) across the EU are



facing increasing barriers in the implementation of their activities. In addition to a shrinking space, CSOs are facing difficulties in securing safe, regular and sustainable funding. As there is a wide discrepancy in the availability of sustainable funding for CSOs across policy areas, CSOs operating in specific sectors are more affected than others. Access to sustainable and reliable funding allows CSOs to plan their activities, advocate for the public interest in policymaking processes, and give a voice to citizens and, in particular, vulnerable groups. Sustainable funding is crucial to guarantee independence in CSOs' work. European institutions play an essential role in supporting CSOs across the Union. This event follows the conclusions of the Conference on the Future of Europe, which calls for a Civil Society Strategy and a structured and guaranteed civil dialogue, as well as the development of the Defense of Democracy Package.

## EUCOPE first episode of the Life Science Lectures webinar series

On May 30, 2023, EUCOPE – the European Confederation of Pharmaceutical Entrepreneurs, hosted the inaugural episode of its Life Science Lectures webinar series, “Attaching conditionalities to incentives: the right path to improve access?” The episode delved into the incentive system outlined in the EU Pharmaceutical Package, with the aim to shed light on how these provisions could impact innovation and access to medicines in the EU. The EU Pharmaceutical Package is a once-

in-a-generation opportunity to foster innovation and ensure a future-proof, crisis-resistant regulatory ecosystem. The EU Commission's proposal aims to address availability, affordability, accessibility, and competition by introducing incentives and requirements for medicine product developers. Striking a balance between incentivising biopharmaceutical companies and ensuring patient access to medications is the overarching goal of the proposal. ELPA Director Milan Mishkovikj was part of the panel, and during the discussion, several views were raised on whether these conditional incentives would stimulate or harm access, innovation, and competitiveness in the EU. Also, throughout the discussion, there was a shared recognition to address unmet medical needs and stimulate innovation in areas that have seen limited progress in recent years.



## EMA meeting on Decentralised Clinical Trials

On July 20, 2023, ELPA Vice President Tove Frisch participated in the joint meeting of the CTTI/FDA Patient engagement Collaborative (PEC) and EMA Patients and Consumers Working Party (PCWP) dedicated to Decentralised Clinical Trials (DCT). During the meeting, the following topics were tackled: trial access, digital health, how to introduce decentralised clinical trials in Europe with so many different health systems, the EU's recommendations on DCT, how future care will look and how to use local health centres with the structures and knowledge that is already present in these units in a way that facilitates the introduction of DCT.

## Economist Impact - 9<sup>th</sup> annual World Cancer Series Europe

The 9<sup>th</sup> Annual World Cancer Series Europe, organised by the Economist Impact, took place in Brussels on September 21-22, 2023. The two-day summit featured over 90 speakers and welcomed an audience representing policymakers, healthcare providers, industry leaders, academics, patient groups and investors. The 2023 agenda was built on last year's themes of innovation, equity and excellence, which lie at the heart of Europe's Beating Cancer Plan. As the plan is implemented, it's time to take stock and ask how the reality of cancer care in the region aligns with targets. The summit identified successes and what still needs attention. Increasing momentum towards achieving the plan's objectives. ELPA President Marko Korenjak participated in the panel 'Effective and equitable screening across Europe.' Screening is critical to cancer control, but implementation can be inconsistent, and not all screening is of equal value. Using screening of lung cancer as an example, speakers considered how to advance screening across Europe while recognising member states' authority to design their own programmes.



## Primary health care policy and practice: implementing for better results

On 23 October WHO/Europe, together with UNICEF and the Government of Kazakhstan, co-hosted an international conference to celebrate the 45<sup>th</sup> anniversary of Alma-Ata and 5<sup>th</sup> anniversary of Astana declarations on primary health care. The conference "Primary health care policy and practice: implementing for better results" was an official side event of the 73<sup>rd</sup> session of the WHO Regional Committee for Europe held in Astana, Kazakhstan, in October 2023. The Conference was aimed at strategic health leadership at national and subnational levels shaping primary health-care and service delivery transformation. In addition, senior officials in ministries of health with technical responsibility for the organisation of primary healthcare services were invited to participate, as academic and technical experts from academic institutions, and



international and non-governmental organisations involved in shaping primary healthcare services. On September 27, 2023, ELPA President Marko Korenjak participated in the pre-conference roundtable discussion 'PHC as a driver of health equity and well-being'.

## EPHA 30<sup>th</sup> Anniversary Conference

On September 12, 2023, ELPA has the honour of celebrating the 30<sup>th</sup> Anniversary of the European Public Health Alliance. EPHA was formed thirty years ago, and the EU Treaty first included a specific reference to Public Health, with this Treaty entering into force only some weeks after EPHA was founded. These last thirty years have seen some great strides in EU public health policy. Especially in tobacco control, and also in some pollution control, as well as latterly in areas of vaccine joint procurement and a coordinated pandemic response. EPHA has built a strong track record of bringing the health concerns and issues relevant to people into EU policymaking – putting the people into Public Health. But it is also the case that much remains to be accomplished and there are policy areas where progress has been only patchy or has stagnated. Threats to Public Health now include social, economic, political and commercial determinants alongside bigger issues such as the Ukraine war, the climate change crisis and the rising trends of populist political power in direct opposition to rational evidence-based policymaking.



## POLITICO Health Care Summit 2023

As every year, ELPA attended the POLITICO Health Care Summit. On October 24-25, 2023, POLITICO organised its annual checkup of Europe's health care sector. The two-and-a-half years have raised important challenges – but have also spawned many opportunities on how to reform and strengthen health care across the board. The European Health Union embodies many of these innovations and aims to establish a robust crisis response system for potential threats. So, what's on the checklist? We need to take stock of the COVID-19 response and apply the lessons learned. The war in Ukraine has set in motion

a movement of people in Europe unprecedented since 1945. Additionally, it has unleashed inflation, piling cost pressures on already strained health services. Other crucial healthcare policy areas in need of medical (and political) attention include the Pharma Strategy, Digital Health, non-communicable diseases, and much more. POLITICO brought together a stellar lineup of speakers for a series of interviews and panel discussions. The seventh edition of the summit represented a convening moment for key policymakers, groundbreaking industry experts, medical professionals, patients' representatives and more to shape the future healthcare policies in the EU.

## UEG Week 2023

ELPA was part of the United European Gastroenterology - UEG Week 2023 in Copenhagen from October 14-17, 2023, to raise awareness of liver diseases. The most important meeting was on October 15, when leading experts in digestive health, together with dedicated patient advocates, convened to launch the Digestive Health Roundtable. This initiative marks the first in a series of multidisciplinary meetings, all driven by a shared purpose – to address challenges, identify opportunities and reach consensus on joint actions aimed at improving digestive health across Europe. During the roundtable, Milan Mishkovikj, ELPA Director, emphasised the significance of prevention in improving outcomes, noting, “There is strong evidence to suggest that many digestive diseases and cancers can be prevented, with liver disease being among the



*Milan Mishkovikj, ELPA Director - Lone McColaugh, President Danish Liver Association - other participants, UEG meeting*

most preventable. To successfully shift our focus from treatment to prevention, a concerted effort at the EU level is needed to manage risk factors effectively. The promotion of healthy lifestyles among the general public, including limited alcohol consumption, a balanced diet and regular exercise, sit at the centre of this.” Also, Lone McColaugh, from the Danish Liver Association - ELPA Member, drew attention to another vital consideration for enhancing the quality of life among patients – the stigma associated with certain digestive diseases and cancers. She said, “The stigma surrounding liver disease has been shown to have a significantly

negative impact on an individual's quality of life. In some cases, it even leads to delayed diagnosis as patients hesitate to seek help due to the negative connotations linked to this disease. It therefore remains essential that we continue to advance our educational initiatives across Europe, aimed at combatting this stigma.”

## Together, Ensuring Deserved Care for Every Liver Cancer Patient

On October 25, 2023, Digestive Cancer Europe - DiCE, organised a high-level event on the occasion of October Liver Cancer Awareness Month. ELPA Director Milan Mishkovikj had the pleasure of addressing the attendees with some welcome



remarks focused on the importance of shaping health policies that include liver cancer screening, and liver cancer should be added to national screening schemes. The agenda was rich in leading expert speakers who provided thought-provoking discussions on crucial topics for the future of liver cancer care. The insightful discussions made this event truly exceptional. It's through collaborative efforts like these that we can make a lasting impact on Liver Cancer care.

## European Society for Medical Oncology (ESMO) 2023

From October 20 to 24, 2023, Milan Mishkovikj, ELPA Director and Dr Teresa Casanovas, ELPA Scientific Committee Leader, attended the European Society for Medical Oncology – ESMO Congress. The ESMO Congress is a highly influential oncology platform for clinicians, researchers, patient advocates,



*Prof Dr Andrés Cervantes M.D., ESMO President - Milan Mishkovikj, ELPA Director - Dr Fabrice André M.D., ESMO President-Elect, ESMO meeting*

journalists and healthcare industry representatives from all over the world. ESMO 2023 worked towards the dissemination of the latest data, providing high-quality education and excellent networking opportunities for oncologists and other stakeholders from all around the world. ESMO's core mission is to improve the quality of cancer care, from prevention and diagnosis all the way to palliative care and patient follow-up. It is to educate - doctors, cancer patients and the general public - on the best practices and latest advances in oncology. And it is to promote equal access to optimal cancer care for all patients.

## European Cancer Summit 2023

This year's edition, which took place on November 14 and 15, 2023, has attracted a record number of delegates joining in Brussels to meet and greet friends and colleagues from across Europe and beyond. As every year, the event showcases our multi-stakeholder, collaborative efforts to bring about more effective, efficient, and equitable cancer care in Europe. Oncology experts, patient advocates, politicians, and policymakers collaborating on the future of cancer care in Europe gathered together to reflect on the greatest challenges that lie ahead, as well as the key priorities and most effective strategies for success. In addition, this year, due to the upcoming EU elections, the European Cancer Organisation launched its Manifesto under the title: 'Accelerating Momentum: A Manifesto to 2030'. ELPA Vice President Ivana Dragojević, during a session dedicated to patients' voices, emphasised the urgent need to address the burden linked to viral hepatitis infections, alcohol, and obesity in relation to liver cancer. Education and early detection, along with eliminating hepatitis B, C, and D, is crucial.



*Ivana Dragojević, ELPA Vice President, European Cancer Summit*

## The BCLC 2023 update

On November 20, 2023, Dr Teresa Casanovas, ELPA Scientific Committee Leader, ELPA Director and ASSCAT President, participated in 'The BCLC 2023 update. Evidence- and value-based approach in real-world practice' conference. The meeting was organised by the BCLC team, a multidisciplinary group located at the Clinic Hospital in Barcelona. The BCLC team is one of the world leaders in the study of liver cancer. During the round table, speakers discussed some circumstances related to the possible complications derived from malnutrition, sarcopenia and fragility of the patient with liver cancer as multidimensional problems, not only physical. Dr Casanovas presented a specific scenario, a patient diagnosed with liver



*Dr Teresa Casanovas M.D., ELPA Scientific Committee Leader and ELPA Director - other participants, The BCLC 2023 update*

cancer and a possible indication of partial hepatectomy as a treatment; some considerations about frailty were commented on, not only physical aspects. Also, she stressed her concerns about recommending overweight patients a restrictive hypocaloric diet without taking into account cirrhosis and particular requirements in order to maintain liver function. These cases should be evaluated by a nutritionist.

## Webinar on the Cancer Inequalities Registry

As a member of the Beating Cancer Stakeholder Group, ELPA attended the webinar on the European Cancer Inequalities Registry on December 13, 2023. As one of the 10 flagships of Europe's Beating Cancer Plan, the European Cancer Inequalities Registry (ECIR) process aims to identify trends, disparities and inequalities between Member States and regions. In highlighting challenges and specific areas of action, it helps Member States identify respective gaps and shortcomings in cancer care and prevention, as well as guide targeted investments and interventions at EU, national and regional level. The Registry process was launched in February 2022 with its first milestone, the ECIR Data Tool, which allows users to explore cancer inequality indicators in an interactive way. The Data Tool and the website are regularly updated and enriched with additional data and indicators as new evidence becomes available. A new section focusing on specific topics and a number of fact sheets have been added this year. The Registry reached its second milestone in February 2023, with the publication of 29 Country Cancer Profiles (EU27, Norway and Iceland). The third milestone of the Registry, for which work is well progressing, is a report on "Beating Cancer Inequalities in the EU: Special focus on cancer prevention and early detection". This report will be ready

in February 2024, starting a biennial reporting cycle, alternating with the Country Cancer Profiles. These key deliverables are complemented by research on specific cancer inequalities, such as an ongoing study by the International Agency for Research on Cancer on socio-economic inequalities. The objective of this meeting was to present the latest developments of the European Cancer Inequalities Registry since the last stakeholder webinar in May 2023.

## **HERA 2023 Conference**

On December 5, 2023, ELPA attended the annual conference organised by HERA, the European Health Emergency Preparedness and Response Authority. Recent health emergencies, notably the COVID-19 pandemic, have highlighted the urgent need for enhanced preparedness measures and stressed the importance of being better equipped to respond to similar challenges in the future. Is now the EU better prepared? That was the theme of the second annual conference organised by HERA in Brussels, gathering 500 participants in person and online. The conference brought together stakeholders from industry, academia, civil society, national, local, and regional authorities, as well as international organisations and partner countries, to ignite reflections on the topics of resilient supply of medical countermeasures, research and innovation for better preparedness, global epidemic intelligence, and the correlation between climate change and infectious outbreaks.

## **Exercise for Health Summit**

The Exercise for Health Summit (EfHS), organised by EuropeActive, kicked off in Madrid on November 22, 2023, with the timing designed to coincide with the Spanish Presidency of the European Council, in the second half of 2023. ELPA representative Veronika Všetickova attended the two-day event designed to explore the opportunities for promoting health-enhancing physical activity and its impact on communities and individuals. The summit affirmed the unequivocal correlation between exercise and health, validating it as a form of medicine when approached with diligence and regularity. ELPA remains steadfast in championing patient needs, advocating for the exercise as a pivotal element in comprehensive healthcare strategies.

## **HMA/EMA Big Data Stakeholder Forum 2023**

As the journey towards data-driven medicines regulation accelerates, the fourth annual Big Data multistakeholder forum took place on December 4, 2023, at the EMA building in Amsterdam, enriched with virtual participation. It aimed to inspire stakeholders with opportunities for the future, discuss data-enabled opportunities to improve medicines' development and regulatory decision-making and inform and strengthen collaboration with stakeholders and partners on the delivery of the data activities, including the Network Strategy to 2025. Many patient representatives attended the forum, including ELPA representatives. Reinforcing patient relevance in evidence generation is a key priority in the EMA's Network Strategy and the realisation of a data-driven regulatory network. Despite much progress in the EU in recent years, more efforts are needed to systematically include Patient Experience Data (PED) in medicines' development and regulation.

# EASL Meetings

## EASL Policy and Public Health Committee meeting

Being Marko Korenjak, ELPA President, part of the EASL Policy and Public Health Committee as a patient representative, he participated in a meeting of the Committee on January 30, 2023. The mission of the Committee is to provide EASL with expert scientific and policy guidance to enable it to carry out its public affairs activities and achieve its public affairs goals and objectives. The Policy and Public Health Committee members are responsible for coordinating the development of the following:

- EASL Policy and Public Health Strategy and Work Plan.
- new EASL Policy Statements, Position Statements, and EASL Public Health Policy Research.
- EASL Public Health sessions at EASL Public Health events.
- EASL cooperation with patient associations working in the field of liver conditions.

## Promoting Liver Health: an urgent Call for Action at WHO

On 22 May 2023, ELPA President Marko Korenjak joined policymakers, thought leaders, Permanent Mission Representatives to the UN, WHO staff, and people affected by liver disease gathering at the EASL Office in Geneva for the invitation-only event on the side-lines of the 76<sup>th</sup> World Health Assembly: “Together for Better Liver Health: Mobilising Action for Fatty Liver Disease”. The aim of the event was to raise awareness on the need for action, and to call for a coordinated response to combat the global public health threat represented by fatty liver disease.



*Together for Better Liver Health: Mobilising Action for Fatty Liver Disease, group picture*

## EASL Liver Cancer Summit

ELPA Vice-President Julio Burman and ELPA Director Prof Gamal Shiha attended the EASL Liver Cancer Summit 2023 on April 20-22. Liver cancer is a significant health problem, and hepatocellular carcinoma (HCC) is considered one of the leading causes of cancer-related deaths worldwide. It is associated with many liver diseases such as Hepatitis B, C and D, excessive alcohol intake, NASH and NAFLD. Recent findings will likely soon transform the way we diagnose liver cancer, screen at-risk patients, and treat patients with primary liver cancer. The Summit 2023 brought together all stakeholders engaged in tackling liver cancer, including clinicians, researchers, policy and public health specialists, nurses and allied health professionals, patient representatives, and industry professionals. The programme of the Summit addressed essential advances in the way we understand the pathogenesis of the two most common primary liver malignancies – hepatocellular and cholangiocellular carcinoma – and discussed the diagnosis and treatment of patients who suffer from these primary liver tumours.



*Prof Dr Gamal Shiha M.D., ELPA Director - Julio Burman, ELPA Vice President, EASL Liver Cancer Summit*

## EASL Congress 2023

As every year ELPA, together with all its members, participates in the EASL Congress. This year the meeting was organised in Vienna on June 21-24, 2023.

9,000 clinicians, researchers, scientists, trainees and postdocs, nurses, allied health professionals, patient representatives, and healthcare industry professionals interacted and expanded opportunities to share research and to network with the global liver community, both onsite and online.

ELPA's active participation in the congress:

- EASL Patient Forum.
- EASL Opening ceremony.
- Press conference.
- Patient organisations sessions at the Public Health Track Hubs – ELPA members' presentations.
- Challenges in screening for NAFLD- or alcohol-related liver disease – ELPA speaker.



*Julio Burman, ELPA Vice President, EASL Congress, The Future of Hepatology/Hepatologists: a mix of opportunities and threats panel*

- The Future of Hepatology/Hepatologists: a mix of opportunities and threats – ELPA part of the panel.
- Multi-society and multi-stakeholder consensus revision of the NAFLD nomenclature: the final results
- PSC Forum 5 for collaborative research SC Forum 5 for collaborative research.



*Prof Dr Thomas Berg M.D., EASL Former Secretary General - Prof Dr Jonel Trebicka M.D., Goethe-Universität Frankfurt am Main, Medical Department I - Prof Dr Aleksander Krag M.D., EASL Secretary General - Milan Mishkovikj, ELPA Director - Julio Burman, ELPA Vice President - Dr Ameli Schwalber PhD, Concentris CEO, EASL Congress*



*Milan Mishkovikj, ELPA Director - Anastassiya Semeiskaya ELPA Office - Eva Perez, FNETH President - Germán Corbacho Carrobes, FNETH Office, EASL Congress*



*Prof Dr Pietro Lampertico M.D., Fondazione IRCCS Ca' Granda, Ospedale Maggiore Policlinico, University of Milan - Prof Dr Fabien Zoulim M.D., Lyon University, Hepatology Department at the Hospices Civils de Lyon, France, Viral Hepatitis Research Laboratory, INSERM U1052, Lyon Cancer Research Center - Julio Burman, ELPA Vice President - Veronika Všetickova, ELPA Head of EU Affairs, EASL Congress*

## EASL SLD Summit 2023

On September 21-23, 2023, ELPA Director Prof Dr Gamal Shiha, ELPA Scientific Committee representative Prof Dr Helena Glasova and Veronika Vsetickova ELPA Head of EU Affairs attended the EASL SLD Summit. The meeting aimed at updating on the most recent advances in SLD research, both pre-clinically and clinically, focusing on MASLD and tackling the issue of MetALD. Participants gained insights in the most key techniques employed in research, clinical trials and clinical practice, with an understanding of their potential as well as limitations. They got the latest update on where we stand with the efforts of having MASLD, and SLD in general, on the agenda as a public health problem and the roadmap and policies to tackle this problem, in which the people living with SLD, and many stakeholders have been increasingly



*Veronika Vsetičková, ELPA Head of EU Affairs - Prof Dr Gamal Shiha M.D., ELPA Director - Prof Dr Helena Glasova M.D., Hep Help Klub, EASL SLD Summit*

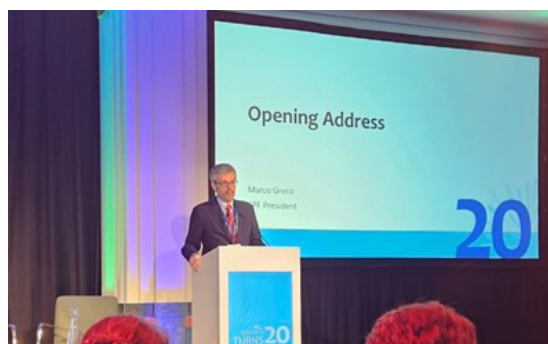
joining forces. In light of the latter, the Summit also provided a space to further discuss the nomenclature change and its potential impact on research clinical practice and awareness. A session was dedicated to discussing in-depth the issue of people who combine alcohol use and metabolic risk factors, designated as MetALD in the latest nomenclature. Attendees also got the latest data on diagnosis and prognostication in MASH and on how to tackle MASLD as a multisystem disease.

## EPF and EUPATI Meetings

ELPA joined the European Patient Forum (EPF) in 2011, and the collaboration is still going on very fruitfully. ELPA started collaborating with EUPATI two years ago and, as a sustainable partner and having many representatives involved in the Fellow Programme, ELPA participated in many meetings.

## EPF's Annual General Meeting 2023 and 20<sup>th</sup> Anniversary Event

On April 29, 2023, representatives from EPF member organisations from across Europe gathered in person, in Brussels, for the Annual General Meeting. ELPA's representative was Director Milan Mishkovikj. During the event, EPF's board members, together with the Secretariat, reported on 2022 activities and gave an overview of the current and upcoming work plan for 2023. The EPF Youth Group contributed to the annual overview by presenting their achievements for 2022 and upcoming events and activities for 2023. This year, five seats in the board were open to re-election and, as the current three-year term of all five members of the Ethics Committee had come to an end, the AGM allowed to elect new members for the Committee. The day before the AGM, it was the occasion to celebrate EPF's monumental achievement: 20 years of building a solid patient voice across Europe. The anniversary event brought together EPF members, partners, key figures from its two-decade history, and staff members in Brussels.



*Dr Marco Greco PhD, EPF President, EPF's Annual General Meeting*

## EUPATI SPA Meeting

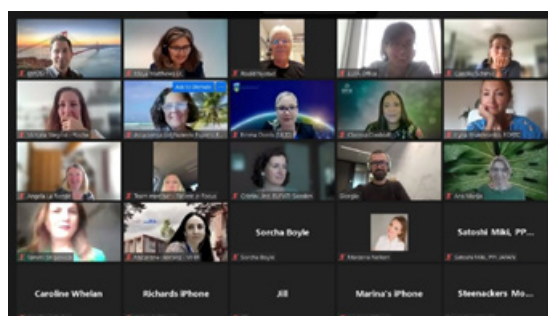
On March 1, 2023, ELPA Representatives participated in the EUPATI Sustaining Partners Meeting. With all the EUPATI partners, they discussed a shared vision and patient-driven approach to improving health outcomes. They also assessed the 2022 achieved milestones reflecting on the future challenges. As



sustaining partner, ELPA will continue working with EUPATI to provide accessible, innovative, and inclusive education to empower patients. EUPATI is a public-private partnership composed of a multi-stakeholder structure representing patient organizations, not-for-profit, the pharmaceutical industry, and academic institutions. EUPATI's strength is its community of dedicated and committed organizations and individuals who believe in its mission to support quality patient engagement through education.

## EUPATI Annual General Meeting 2023

As a sustaining partner, ELPA participated in the EUPATI Annual General Meeting on September 28, 2023. 43 partners and 24 EUPATI National Platforms gathered to discuss the achievements from last



year and the next steps. We were delighted to have Maya Matthews from the European Commission DG SANTE as our keynote speaker.

## ELPA in international meetings

### HepC in Pregnancy: Strategies to Improve Linkage to Care and Treatment

On January 25, 2023, ELPA Vice President Ivana Dragojević attended the webinar 'HepC in Pregnancy: Strategies to Improve Linkage to Care and Treatment'. Although routine antenatal testing for hepatitis C is increasing, there is limited guidance regarding hepatitis C treatment when it comes to best practices regarding hepatitis C treatment for individuals diagnosed during pregnancy. As a result, very few individuals diagnosed with HCV in pregnancy are successfully treated, and they remain exposed to the ongoing risks associated with chronic hepatitis C infection. This webinar is the second of a three-part series organised by the Coalition for Global Hepatitis Elimination.

### 18<sup>th</sup> Global Hepatitis Summit - GHS 2023

The Summit, a 50-year legacy of the International Symposium on Viral Hepatitis and Liver Disease (ISVHLD), was held on April 25 – 28, 2023. ELPA President Marko Korenjak was invited to speak about how to engage policymakers and patient advocacy groups in liver disease. 2023 Summit featured a unique interdisciplinary meeting designed to share the latest developments in all aspects of liver diseases, including viral hepatitis, non-alcoholic fatty liver disease, hepatocellular carcinoma and so on. It encompassed the continuum of research from basic science to clinical research and public health applications. GHS 2023 was as much a networking event as a cutting-edge research conference, featuring dedicated tracks for health practitioners and inspiring workshops for those working in the liver and hepatitis space, where renowned speakers highlighted the most exciting recent results in the field and provided perspectives for research and patient management. The multidisciplinary focus for all areas of interest included basic science, translational research, development of novel diagnostic tools and therapies, and approaches to control and eliminate liver diseases as public health threats.



## VHPB Technical Meeting

On April 4-6, 2023, the Viral Hepatitis Prevention Board organised a meeting to talk about the role of international organisations in eliminating viral hepatitis in Europe. ELPA Vice-President Ivana Dragojević discussed with the participants achievements, challenges and the way forward towards elimination.

Meeting Objectives:

- Provide an overview of the current viral hepatitis situation in Europe in relation to the renewed WHO global health sector strategies for 2022-2030.
- Discuss initiatives, achievements, best practices and challenges from international organisations in the prevention and control of viral hepatitis.
- Assess the need to achieve the elimination of viral hepatitis as a significant public health threat by 2030 as set out in the new WHO Global Health Sector Strategies 2022-2030.
- Investigate potential collaborations.
- Discuss successes, good practices, issues and barriers to overcome and the way forward.

## Global Patient Partnership – Summit 2023

ELPA attended the Global Patient Partnership Summit 2023 in Vienna to Discuss Patient Engagement on May 22 – 24, 2023. The summit aimed at exploring the crucial role of patients in their relationships



*Julio Burman, ELPA Vice President, Global Patient Partnership Summit 2023*

with stakeholders within the healthcare industry. The event witnessed the presence of various influential organisations representing a wide range of health conditions, including diabetes, obesity, cardiovascular problems, renal diseases, and liver diseases. ELPA representative was Vice-President Julio Burman who had the possibility to interact with patient advocacy groups, healthcare providers, industry representatives, and policymakers. The participants engaged in insightful discussions, sharing experiences and best practices regarding patient engagement, empowerment, and involvement in decision-making processes.

## Surfing The NASH Tsunami Podcast

Thursday, June 8 was International #NASHDAY 2023, and the podcast hosted a special session featuring patient advocates **Gina Villiotti Madison**, ELPA President **Marko Korenjak** and **Michael Betel**. With co-hosts **Louise Campbell** and **Roger Green**, the group shared both a positive and sobering



discussion around the Fatty Liver public health epidemic and its impact on younger generations now and into the imminent future. This was a particularly important and moving episode that captured a range of topics pertinent to the patient perspective and, more broadly, stepping up to NASH.

## Paris NASH Meeting

The 9<sup>th</sup> International Think Tank Paris NASH Meeting brought together a diverse faculty of key opinion leaders from the US and Europe, fostering transatlantic scientific collaboration. This event featured engaging sessions with expert-led discussions and research presentations. Interactive workshops and abstract-driven programming ensured a dynamic and enriching experience for all attendees.

ELPA representative was Dr Teresa Casanovas ELPA Director and Scientific Committee Leader, who attended the meeting on September 7 and 8, 2023.

## ILCA Annual Conference 2023

ELPA Director Milan Mishkovikj and ELPA Vice President Julio Burman attended the ILCA Annual Conference on September 7-9, 2023. The Annual Conference solidifies an ongoing commitment to connect and inspire liver cancer specialists worldwide with outstanding education and thought leadership. The 17<sup>th</sup> edition of the ILCA Annual Conference has been a great success, thanks to the active participation of our attendees and speakers coming from across the world. ILCA's Annual Conference is the world's top meeting for liver cancer specialists, providing the perfect platform to share the latest research and techniques, as well as the basic science every professional in the field must master. The conference is a multidisciplinary event, featuring state-of-the-art lectures, cutting-edge symposia, and the ILCA Tumor Board - a must-attend forum for education and advancement in liver cancer, very interesting also for patient advocates.



*Milan Mishkovikj, ELPA Director – Prof Dr Bruno Sangro M.D., Clínica Universidad de Navarra -Julio Burman, ELPA Vice President ILCA Annual Conference*

## AASLD The Liver Meeting 2023

A small ELPA delegation composed by ELPA Vice Presidents Ivana Dragojević and Julio Burman, and ELPA Director Milan Mishkovikj attended the annual AASLD The Liver Meeting from November 10 to 14, 2023. The American Association for the Study of Liver Diseases (AASLD) Congress stands as a premier platform where healthcare professionals, researchers, patients and industry experts converge to share knowledge, exchange ideas, and foster collaboration. Participation in this event is not merely attendance; it is an active engagement that propels the field of hepatology forward and enhances the transformative impact it has on the landscape of liver-related research and healthcare.



*Michael Betel, Fatty Liver Alliance President - - Milan Mishkovikj, ELPA Director - Julio Burman, ELPA Vice President AASLD The Liver Meeting*

## Second Annual Primary Care NAFLD and NASH Summit

On December 7, 2023, ELPA President Marko Korenjak opened the Second Annual Primary Care NAFLD and NASH Summit. He shared the opening remarks with Michael Betel, president and founder of Fatty Liver Alliance, the Canadian association organising the meeting. This year, the summit brought together



*Michael Betel, Fatty Liver Alliance President- Marko Korenjak, ELPA President, Second Annual Primary Care NAFLD and NASH Summit*

experts from various fields to discuss the latest research, diagnostic tools, and treatment strategies for non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH). To give you an overview of the content, the summit was divided into eight sessions, covering topics such as epidemiology, pathogenesis, diagnosis, management, referral and collaboration, the patient perspective, case studies, and panel discussions. Distinguished speakers provided valuable insights on the current state of NAFLD and NASH, as well as the importance of early detection, interdisciplinary

collaboration, and patient-centered care. Furthermore, it focused on the importance of a multidisciplinary approach to patient care, the role of primary care physicians and nurse practitioners in facilitating referrals, and the benefits of effective communication and collaboration between healthcare professionals. In addition to the informative presentations, the summit featured a patient perspective session to hear firsthand about the challenges and impact of living with NAFLD and NASH on patients' physical, emotional, and social well-being. This session aimed to highlight the importance of a patient-centred approach in managing these conditions and identify strategies to involve and empower patients in their own care. Finally, a case study was presented and a panel discussion involving a primary care physician, a nurse practitioner, a hepatologist, and an endocrinologist wrapped up the event.





**EMPOWERING  
OUR MEMBERS**



## ELPA Directors' visit to the Egyptian Association of Liver Patients' Care – ALPC

In February 2023, on World Cancer Day 2023, ELPA Board was invited to Mansura, Egypt, by Prof Dr Gamal Shiha, ELPA Director and CEO of the Association of Liver Patients' Care, ELPA founder member. They had the occasion of visiting the Egyptian Liver Research Institute, the Technical Institute of Nursing, the Smart Biomaterials Research Centre and the Egyptian Liver Hospital (ELRIAH), where a medical staff of about 500 people care for around 50,000 patients per year. The Egyptian association has been doing a remarkable job in fighting liver diseases, working with multidisciplinary teams and establishing a multi-stakeholder approach, collaborating with the Ministry of Health, scientists, government bodies, corporate industry, local governments and local businesses. The association also achieved one of the most remarkable goals in Hepatitis elimination. With the micro-elimination project "HepCFreeVillages", the organisation managed to reach 106 villages, screen 350,000 people, detecting and treat 15,000 people for HCV. This was a great learning opportunity and a fruitful possibility to share experience and knowledge. ELPA is grateful for Prof. Gamal and his team's hospitality.



*Veronika Všetickova, ELPA Head of EU Affairs - Marko Korenjak, ELPA President, Tove Frisch, ELPA Vice President - Milan Mishkovikj, ELPA Director - Prof Dr Gamal Shiha M.D., ELPA Director - Dr Teresa Casanovas M.D., ELPA Scientific Committee Leader and ELPA Director - Beatrice Credi, ELPA Head of Office - Ivana Dragojević, ELPA Vice President, visit to the Egyptian Association of Liver Patients' Care – ALPC*

## ELPA visiting its member in Madrid

In March 2023, ELPA Vice-President Julio Burman visited one of the Spanish ELPA members based in Madrid: the National Federation of Liver Patients and Transplanted, FNETH. He spent two days visiting the association and hearing from its President, Eva Perez, and other representatives about their activities and future plans. The visit opened future collaboration between ELPA and its members, especially in the field of transplantation, considering the expertise acquired over many years of fieldwork by FNETH.



*Eva Perez, FNETH President - Julio Burman, ELPA Vice President, ELPA visiting its member in Madrid*

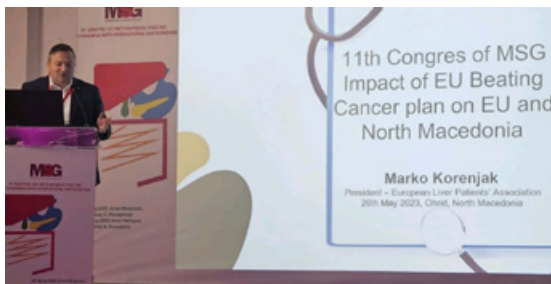
## LIVERO Conference. Elimination of viral hepatitis, a tangible objective in Romania

On April 21, 2023, ELPA Vice-President Ivana Dragojević was invited to speak at the conference, where she discussed with the participants patient empowerment and how to reduce screening programs inequities. Organised in collaboration with ELPA member from Romania APAH-RO, the meeting was the occasion to present the conclusions from the LIVERO screening programs and the gained experience and future intervention paths in viral hepatitis. In addition, speakers and attendees focused the debate on the new challenges in liver pathology: chronic non-communicable diseases and liver cancer.



*Ivana Dragojević, ELPA Vice President - other participants - Marinela Debu, APAH-RO President, LIVERO Conference*

## 11<sup>th</sup> Congress of the North Macedonia Society of Gastroenterology and Hepatology



ELPA President Marko Korenjak participated in the 11<sup>th</sup> Congress of the North Macedonia Society of Gastroenterology and Hepatology, bringing a unique perspective and valuable insights to the discussions from the liver patients' point of view. He presented the impact Europe's Beating Cancer Plan has on the EU and on North Macedonia on May 26, 2022. The congress was organised in collaboration with ELPA member Hepar Centar Bitola and the University Clinic for Gastroenterology and Hepatology.

## ELPA@home Turkey – LAL-D

The ELPA@home Turkey – LAL-D took place in Istanbul on June 1 and 2, 2023. Organised by ELPA in synergy with its Turkish member HEPYAŞAM, the meeting aimed at learning about the situation of LAL-D in Turkey to look for ways to find patients. Participants heard from physicians, Gastro paediatric doctors, GPs, Hepatologists, Mr Eduardo Lopez from the AELALD Spain association, the activities of the Rare Disease Department of the Ministry of Health, the Rare Diseases Patient Association and the Liver patient association. Participants defined the barriers and possible solutions to find the patients. An action plan was developed and will be implemented by the Liver Association and the Association of Rare Diseases with the collaboration of all the present stakeholders. A Declaration was signed with the participants' commitment to work together on the action plan. Here is a summary of the future steps:

- Inform the community about LAL-D disease.

- Make this information systematically through social media and classical media.
- Cooperate with municipalities to organise awareness meetings in regions where consanguineous marriages are common.
- Cooperate with doctor associations asking for lists of doctors who will meet with gastro, paediatrics and metabolism associations.
- Ask to be an observer in the studies of the Ministry of Health on rare diseases, trying to increase the focus on LAL-D.
- Participation of HEPYASAM in the rare diseases network.
- Establish contact with rare disease units established in some universities.
- Advocate to include LAL-D in newborn screening studies.
- Convey the message that babies diagnosed with the disease also have the right to a healthy life and access to treatment.
- Participants agreed to have a virtual meeting at the beginning of September 2023 to follow up on the plan's implementation.



*ELPA@home Turkey – LAL-D, Group Picture*



*ELPA@home Turkey – LAL-D, Group Picture*

## Patient Engagement Open Forum - PEOF

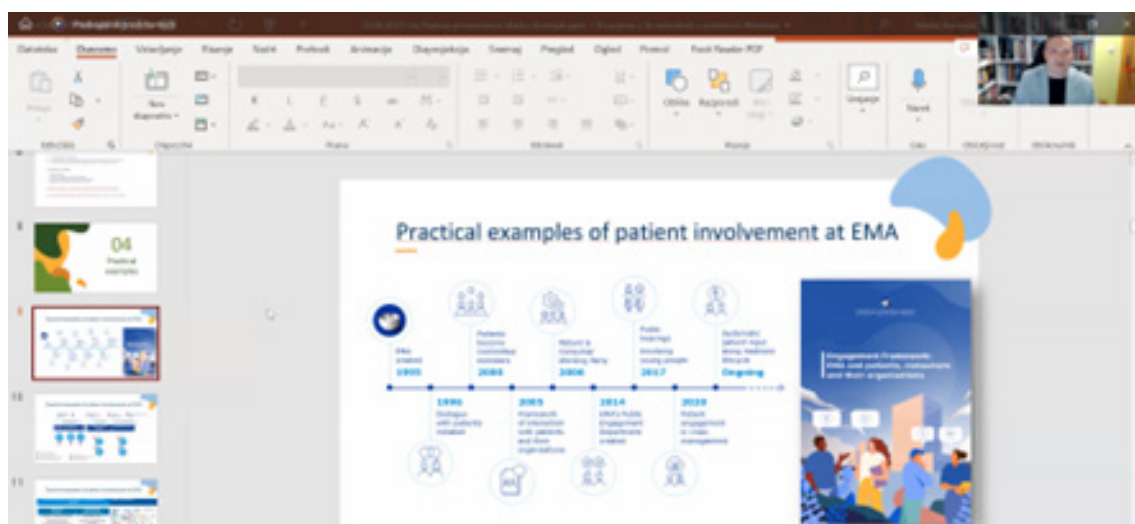
Jointly organised by PFMD, EUPATI, and EPF, PEOF is an event during which participants explore patient engagement working in a multi-stakeholder context. PEOF is composed of virtual sessions on critical topics throughout the year, and a special spring edition of a face-to-face event was held on June 13-15, 2023. ELPA Director Milan Mishkovikj participated in three dynamic days of engaging sessions, networking opportunities, and one-of-a-kind gathering. The lively debates have been the occasion to generate new ideas and innovative solutions with key champions in patient engagement, co-create with patients & gain an understanding of patient needs and preferences, and address hard topics in a non-competitive environment leading to tangible outcomes.



*Milan Mishkovikj, ELPA Director, PEOF*

## Lecture at the University of Padova

In June 2023, ELPA, under the guidance of Prof. Dr Paolo Angeli, had the privilege of being invited by the University of Padova to conduct a specialised teaching session during the renowned “Advanced Educational and Training Course on Clinical Research.” Marko Korenjak, representing ELPA, contributed expert insights on actively involving patients in research endeavours. The course presented exemplary case studies from EMA (European Medicines Agency) and ELPA, highlighting the practical implementation and positive impact of patient involvement on medical advancements. Engaging discussions revolved around the future of patient involvement and its implications for shaping healthcare. ELPA remains dedicated to fostering awareness, offering support, and advocating for liver patients across Europe. Grateful for the opportunity,



ELPA looks forward to continued collaboration with the University of Padova in advancing clinical research and patient care.

## **ECPO - Obesity Science and NCDs Awareness Training Learning Academy**

ELPA representatives attended the workshop organised by the European Coalition for People living with Obesity – ECPO on December 9-10, 2024, in Budapest. The training focused on obesity science and NCDs awareness and represented a great opportunity to gather liver patients and people living with obesity communities to discuss common challenges and solutions. ECPO works collaboratively across Europe to improve the lives of people who are living with and are affected by the chronic disease of obesity through advocacy, policy and education.



*Vicki Mooney, ECPO Executive Director Sólveig Sigurðardóttir, ECPO President - Marko Korenjak, ELPA President – Hanen Samouda, ECPO Director of Education - Veronika Všetickova, ELPA Head of EU Affairs*





# **STRENGTHENING OUR ASSOCIATION**



## ELPA Annual General Meeting 2023 and educational training

As every year, during the EASL Congress, ELPA convened its **Annual General Meeting**. On June 21, 2023, ELPA members all gathered for this special occasion, voted on the Annual and Financial Reports 2022 but also had the possibility to share good practices and talk about the work done so far.

On the same day, in the afternoon, ELPA organised **Educational Training** for its members. Representatives from Mirum Pharma, Cellaion, and CymaBay presented the update from their companies in the field of rare liver diseases, PBC and a broad spectrum of liver diseases, from life-threatening acute-on-chronic liver failure (ACLF) and acute alcoholic hepatitis (AAH) to intermediate severity acute decompensation of cirrhosis (AD) and progressive chronic liver diseases caused by non-alcoholic steatohepatitis (NASH).



## ELPA meetings in Malta

ELPA members gathered in Malta for their annual meetings from November 15 to 19, 2023. Hosted by the Malta Health Network and its chairperson, Gertrude Buttigieg, they had the honour of meeting with the President of Malta, His Excellency Dr **George Vella**, and the Minister for Active Aging, Hon. Dr **Jo Etienne Abela**. The entire group exchanged thoughts with both politicians about liver health and shared with them good practices to advance liver patient advocacy in this field. This was also the occasion to organise an Extraordinary



*Marko Korenjak, ELPA President - Hon. Dr Jo Etienne Abela, Minister for Active Aging*



*Marko Korenjak, ELPA President - His Excellency Dr George Vella, President of Malta*



*ELPA Extraordinary General Meeting, Group Picture*

General Meeting and the usual stakeholders' meeting, during which some ELPA stakeholders presented their plans for 2024.

## ELPA Stakeholders' Meeting 2023



*ELPA Members – Group Picture*

Every year, ELPA organised a meeting inviting its major partners and stakeholders in the field of patients' advocacy in liver diseases. The ELPA Stakeholders' Meeting 2023 took place on November 18, 2023 in Malta. It was a great moment of exchange and networking among ELPA members and representatives from many different associations and international organisations.



*ELPA Stakeholders' Meeting, Group Picture*

Speakers:

- **Kaisa Immonen**, Patient Liaison Expert EMA.
- Prof. **Shira Zelber-Sagi**, PhD, EASL Public Health Councillor-elect, Head of School of Public Health, University of Haifa, Israel.
- Prof Dr **Tim Meyer** MD PhD, ILCA President-Elect, ILCA Systemic Therapy Guideline Committee Chair.
- **Jessica Hicks**, World Hepatitis Alliance.



# **ELPA IN SCIENTIFIC RESEARCH PROJECTS**



ELPA continued to join and participate in numerous EU projects, mainly in disseminating and “translating” medical and scientific objectives and results to the general public, patients, and relatives. Since January 2022, ELPA has been part of the consortium of the following EU projects funded by Horizon 2020: Liverscreen, LiverHope, Decision, Galaxy, MICROB-PREDICT, IPCureB, A-Tango, and FisPlat (EITHealth). In addition, it is part of ESCALON, COBALT and FACILITATE. In 2023, ELPA worked with many partners on new collaborations in the framework of the new EU Horizon Programme, waiting for the evaluation and approval of more projects. 2 more were confirmed: GENIAL and Livation.



LiverScreen has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847989



LIVERHOPE has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 731875



IP-cure-B has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847939



MICROB-PREDICT has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825694



GALAXY has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 668031



DECISION has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847949



A-TANGO has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 945096



ESCALON has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825510



Artemis Project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101136299



Livation Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101104360



THRIVE Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101136622



GENIAL Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101096312



LEOPARD Project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement No 101080964



HL4EU Project has received funding from the European Union's Erasmus+ programme for education, training, youth and sport under grant agreement No 101133773



GRIPonMASH Project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132946. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, Efpia, EuropaBio, MedTech Europe, Vaccines Europe and Mercodia Aktiebolag, Metadeq Limited and Julius Clinical Research BV.



LIVERAIM Project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No 101132901. The JU receives support from the European Union's Horizon Europe research and innovation programme and EFPIA, COCIR, MedTech Europe, Vaccines Europe and EuropaBio.



FisPlat has received funding from the EIT Health under grant agreement No. 20308



## Medical research project Galaxy, Horizon 2020

Medical research project GALAXY brings together partners with unique research competences in clinical hepatology, microbiome, multi-omics, biomarkers and bioinformatics. The aim of the project partners is to develop novel systems medicine tools which integrate clinical, multi-omics and lifestyle information from alcohol over-users at various stages of the disease and healthy individuals in order to: 1) identify signatures of host-microbial cross-talk during disease development and progression, 2) translate this into biomarkers for diagnosis, stratification and treatment monitoring in alcohol over users, and 3) evaluate new interventions to modulate gut microbiota towards prevention and mitigation of the disease in at-risk individuals. Project partners will also study societal and economic impact of medical research project GALAXY biomarkers and treatments to accelerate future development.



## Medical research project Liverhope, Horizon 2020

The objective of Liverhope is to evaluate a novel therapeutic strategy for patients with decompensated cirrhosis based on targeting the main pathophysiological mechanisms of disease progression in cirrhosis, namely the impairment in the gut-liver axis and the persistent hepatic and systemic inflammatory response.

This dual therapeutic approach is supported by preclinical data showing that rifaximin modulates the disturbed microbiota and decreases gut permeability and systemic endotoxin levels characteristics of cirrhosis. Moreover, simvastatin decreases systemic and hepatic inflammation, improves the altered hepatic microcirculation, decreases portal hypertension, and reduces fibrosis progression.



## Medical research project Microb-Predict, Horizon 2020

Within medical research project Microb-Predict, project partners are investigating the human microbiome to identify predictors and mechanisms associated with the development of decompensation of cirrhosis and progression to acute-on-chronic liver failure (ACLF) and death. The project gathers 22 partner organizations working in different fields.



## Medical research project Liverscreen, Horizon 2020

The aim of medical research project LiverScreen is to develop a targeted screening methodology to identify persons with asymptomatic liver fibrosis and cirrhosis among the general population. This methodology involves:

- 1) identification of groups from the general population at high risk of having chronic liver disease,
- 2) screening their liver stiffness with the innovative transient elastography (TE) technology (until now only validated in patients with known liver disease) for diagnosis, and
- 3) determining the right follow-up screening regime. Within the LiverScreen project 8 European countries are collaborating and performing research in over 34,000 subjects to develop the screening methodology and demonstrate its accuracy, clinical value, costeffectiveness, acceptability, and potential to be implemented by healthcare systems throughout Europe.



## Medical research project IP Cure B, Horizon 2020

The objective of the EU-funded medical research project IP-cure-B « Immune profiling to guide host-directed interventions to cure HBV infections» is to develop novel curative concepts for chronic hepatitis B (CHB). The project aim is to improve the cure rate of CHB by boosting innate immunity with immune modulators and stimulating adaptive immune responses with a novel therapeutic vaccine. Researchers are also identifying immune and viral biomarkers for patient stratification and treatment response monitoring. Integration of biological and clinical data enable models for the best combination treatment and effectiveness of novel

curative therapies with respect to disease spectrum and patient heterogeneity. The preclinical platform will be evaluated in humanised mice, combining immune-modulatory strategies to stimulate innate immunity, rescue exhausted HBV-specific T cells and generate anti-HBV adaptive responses. Proof of concept is to obtain in a clinical trial of a combination of novel compounds stimulating innate immunity.



### **Medical research project FiSplat, European Institute for Innovation and Tehnology – EIT Health**

FibroScan Screening Platform (FiSPlat) assess the presence of significant liver fibrosis with an accuracy at least equivalent to the one of the current FibroScan devices (with a sensitivity of 93% and a specificity of 78% using a cutoff of 9.2 kPa). An ergonomic, training procedure, results output and interpretation assistance and an innovative business model, makes the technology usable in a cost-effective manner for mass screening by nurses and general practitioners. This allow earlier decision-making and a personalized follow up. All together prevent the progression of the disease to liver cirrhosis, its associated worldwide morbidity and mortality, as well as reduce liver cirrhosis management costs.



### **Medical research project Decision, Horizon 2020**

The objective of medical research project DECISION is to enhance our understanding, at systems level, of the pathophysiology of decompensation of cirrhosis leading to ACLF or death. For that purpose, project partners perform a multi-omic profiling of already existing large and clinically well characterized cohorts including 2,200 patients with available standardized biobank samples. The gained knowledge during the process allows the development of prognostic and response tests and of combinatorial therapies tailored to the needs of individual patients or identified groups of patients with acute decompensation of cirrhosis. All these efforts aim to decrease the risk of short-term death of patients with acute decompensation of cirrhosis.



## Medical research project A-TANGO, Horizon 2020

In Europe, about 30,000 people die every year from alcohol related cirrhosis, a form of chronic, non-communicable disease. The patients that are at highest risk of death are those with superimposed alcoholic hepatitis (AH) who do not respond to therapy and develop acute on chronic liver failure (ACLF), a newly described syndrome characterised by multiorgan failure. Treatment of ACLF is an unmet need. Based upon their clinical and pre-clinical studies, the A-TANGO consortium aims to perform Phase 2 clinical trials of a novel, patented and innovative therapeutic strategy by repurposing a toll-like 4 receptor antagonist (TAK242, Technology Readiness Level (TRL) 8), which targets inflammation, and combining it with granulocyte colony-stimulating factor (G-CSF, TRL9) that improves hepatocyte proliferation (G-TAK, TRL4). A successful trial will advance G-TAK to TRL8. Additionally, A-TANGO aims to discover novel biomarkers for patient selection and defining prognosis, building health economics models and reimbursement strategies to allow maximal dissemination and exploitation.

## ESCALON

### ESCALON

ESCALON is a project involving a unique team of specialists in different areas (both academic and geographical areas) that aims to create databases and biobanks (both cross-sectional and prospectively) to evaluate biomarkers in blood that could predict hepatocellular carcinoma, cholangiocarcinoma and gallbladder cancer. The project considers various clinical, environmental and genetic factors for each cancer that could shed light on the mechanisms leading to carcinogenesis and help us understand potential prevention points. The study will lead to the discovery and utilization of biomarkers that could be applied worldwide for early diagnosis and detection of hepatocellular carcinoma, cholangiocarcinoma and gallbladder cancer, improve the understanding and provide identification of risk factors associated with hepatobiliary carcinogenesis that could be targeted for prevention and treatment of such cancers. The consortium is formed by physicians, scientists, epidemiologists, statisticians and media specialists in multiple countries across Europe and South America. Each task, designed to work on a different hepatobiliary cancer, is led by a centre in one continent in close collaboration with a centre in a different continent (Europe and South America).



## COBALT

The Covid-19 pandemic has disproportionately affected liver patients - patients with chronic liver disease have around 5-times increased mortality from Covid-19 compared to individuals without liver disease. Therefore, the development of vaccines is a welcomed step, but we don't yet know if they are fully protected in liver patients. Early data from the US demonstrates that two-thirds of liver transplant patients don't have detectable antibodies to the coronavirus after one dose of the mRNA vaccine (Boyarsky et al., 2021). Therefore, there is an urgent need to determine how effective these vaccines are in liver patients to determine if extra protection is needed - such as extra vaccine doses, additional medications, or continued shielding. The COBALT study is taking place across Europe to urgently address this question by measuring responses to vaccination in liver patients. It is designed to report back quickly to inform patients and policy-makers, although further support is needed to accelerate this process and make policy decisions rapidly.



## FACILITATE

FACILITATE is a 4-year project launched by the Innovative Medicines Initiative (IMI) whose primary aim is to enable clinical trial participants to access and make use of their personal health data gathered during studies to allow a better shared medical decision-making with the health professionals involved in their care and to create a process that allows data to be also re-used in future research. Its overall goal is to develop an innovative data-sharing and re-use process within a General Data Protection Regulation (GDPR) compliant and approved ethical framework, not only to allow the access and portability of patient data but also to change the role of patients in the strategy and design of clinical trials – with many new rights and responsibilities – becoming an active component of the drug development process.



## Medical research project GENIAL, Horizon Europe

Alcohol-related hepatocellular carcinoma (ALD-HCC) is, in Europe, the leading cause of liver cancer (2<sup>nd</sup> most common cause of cancer-related death worldwide, affecting both men and women). GENIAL brings together partners with unique expertise in clinical hepatology, single-cell and spatial multi-omics, artificial

intelligence (AI) and communication and dissemination capacities. The aim is to 1) portray genetic and environmental determinants promoting ALD-HCC; 2) evaluate how they interact at cellular level in human samples and preclinical models to get novel insights into liver carcinogenesis, and identify chemopreventive targets; and 3) assess how these determinants modulate the ALD-HCC risk in prospective cohorts of patients included in HCC surveillance programs. Environmental factors will be comprehensively characterised in an ongoing clinical trial designed to evaluate alternative methods for early-stage HCC detection. Finally, AI models, reaching the minimal viable product stage by the end of GENIAL, will be used to integrate genetic and non-genetic information (including digital imaging) to develop novel cost-effective strategies towards prevention and early-stage detection of ALD-HCC in at-risk individuals.



## Medical research project Liveration, Horizon Europe

Colorectal cancer (CRC) ranks fourth in cancer deaths worldwide. Between 20% and 30% of patients with advanced CRC have liver metastases (CRLM). Liver cancer ranks second in cancer deaths worldwide, including hepatocellular carcinoma (HCC). Despite recent advances, liver resection offers the only chance of cure for patients with liver metastases. However, the recurrence rate of these tumours is high even after post-resection. The presence of positive margins in the remaining liver after resection correlates with increased local recurrence and decreased overall survival, the only factor where prognosis could be influenced by the performance of surgery. However, at present, the extent of an R-negative status remains debatable and varies widely from one publication to another. Currently, there are radiofrequency ablation studies that, based on preliminary retrospective human clinical trials, are able to correlate an additional coagulation of tumor margins with a reduction on local recurrence. However, there is no prospective and pragmatic controlled study that accurately measures this additional margin and its impact on oncological outcomes. The aim of LIVERATION is to conduct an ambitious, pragmatic multicenter clinical trial with 720 patients with CRLM and HCC at 24 clinical centres in 6 different countries to determine whether additional ablated margin produced by radiofrequency can decrease the recurrence rate and improve patient survival.

*Being part of many medical research projects, ELPA representatives participated in many meetings and initiatives to implement and monitor them.*

## **MICROB-PREDICT General Assembly meeting**

On January 17 – 19, 2023, ELPA attended the MICROB-PREDICT General Assembly as one of the project's partners. ELPA President Marko Korenjak presented the communication and dissemination data and activities for the year 2022. He also explained how social media could support academic careers during a workshop specifically dedicated to this topic. MICROB-PREDICT aims at developing personalised, microbiome-based treatment strategies to prevent and treat decompensated cirrhosis and acute-on-chronic liver failure (ACLF) and reduce mortality by investigating the human gut microbiome. The goal is to identify predictors and mechanisms associated with the development of decompensated cirrhosis and its progression to ACLF. The need for personalised treatment strategies becomes apparent when considering that there are substantial, yet still largely unexplained, individual differences in developing decompensated cirrhosis and ACLF. At the same time, this observation bears the chance for more effective, more individualised and more targeted treatments.



*MICROB-PREDICT General Assembly, Group Picture*

## **FACILITATE Webinar**

Some ELPA representatives participated in a Webinar organised in the framework of the FACILITATE project on January 27, 2023. FACILITATE is a 4-year project launched by the Innovative Medicines Initiative (IMI) whose primary aim is to enable clinical trial participants to access and make use of their personal health data gathered during studies to allow a better shared medical decision-making with the health professionals involved in their care and to create a process that allows data to be also re-used in future research.

Its overall goal is to develop an innovative data-sharing and re-use process within a General Data Protection Regulation (GDPR) compliant and approved ethical framework, not only to allow the access and portability of patient data but also to change the role of patients in the strategy and design of clinical trials – with many new rights and responsibilities – becoming an active component of the drug development process.

The project will first seek to create an ethical, legal, and regulatory ecosystem that provides clear rules for all stakeholders who are engaging patients and managing their very important health data. With that framework in place, FACILITATE will then aim to develop technological solutions to support the sharing and re-use of data as agreed, first, with the patients.

The idea is that patient study data could be available for cross-referencing with other repositories – improving upon the current situation, in which clinical data are siloed in separate repositories and unable to be used outside of the clinical trial. FACILITATE will ensure that the whole process, from the collection of data to its destruction or anonymisation, including its sharing and re-use, is legally and ethically compliant and aligned with the study participants but also hospitals, academia, and industries' voice.

## DECISION, Second patient and layman event

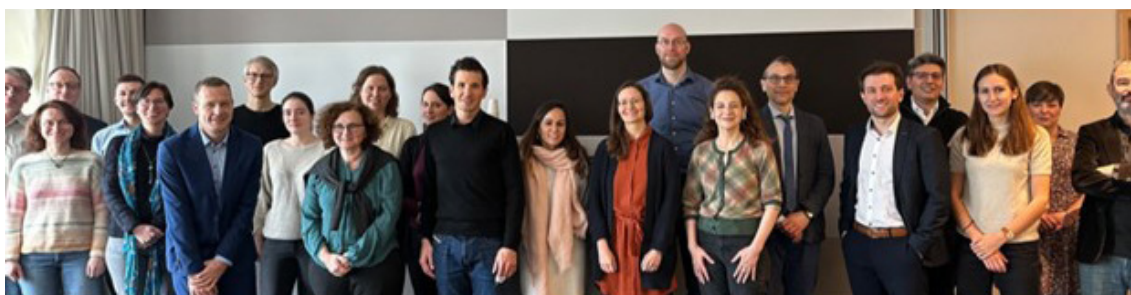
In this event organized by ELPA with the title 'The COMBAT-trial: A novel COMBinATorial therapy with albumin and enoxaparin in patients with decompensated cirrhosis at high risk of poor outcome,' experts from DECISION explained the upcoming clinical trial to patient representatives. They discussed the recruitment process and what it means from an ethical perspective. Great interest was shown in the question of how patient representatives and clinicians can work together to facilitate recruitment for this trial. The meeting took place on March 6, 2023.

DECISION strives to understand better the pathophysiology of decompensated cirrhosis leading to acute-on-chronic liver failure (ACLF) at the systems level by taking advantage of existing large and clinically well-characterized patient cohorts. The goal is to significantly reduce mortality through combinatorial therapies tailored to individual patients' specific needs. Part of this endeavour is to develop a reliable prognostic test to identify patients that are at risk for a poor outcome following standard therapy but who may benefit from a novel and personalised combinatorial therapy and a robust response test to predict the success of a novel combinatorial therapy as opposed to more aggressive solutions like a liver transplant.



## GENIAL, kick-off meeting

ELPA is part of the new medical, scientific project GENIAL responsible for communication and dissemination. The kick-off meeting was organised in Brussels on March 21-22, 2022. Alcohol-related hepatocellular carcinoma (ALD-HCC) is, in Europe, the leading cause of liver cancer. ALD-HCC has a median 5-year survival rate of 15%. Yet, the prognosis is driven by the tumour stage, with curative options providing a 5-year survival exceeding 70% for early-stage HCC (<20% of cases). Therefore, interventions aiming to improve prevention and early detection are key. ALD-HCC results from the interplay between environmental determinants and genetic variations. A comprehensive characterisation of environmental factors (e.g. diet, lifestyle) linked to ALD-HCC is still lacking. The 1<sup>st</sup> genome-wide association study of ALD-HCC was recently performed, identifying predisposing genetic variations. However, their role in alcohol-related liver carcinogenesis needs clarification, and the genetic architecture of ALD-HCC remains mostly unknown. GENIAL brings together partners with unique expertise in clinical hepatology, single-cell and spatial multi-omics, artificial intelligence (AI) and communication and dissemination capacities. The aim is to 1) portray genetic and environmental determinants promoting ALD-HCC; 2) evaluate how they interact at the cellular level in human samples and preclinical models to get novel insights into liver carcinogenesis and identify chemopreventive targets; and 3) assess how these determinants modulate the ALD-HCC risk in prospective cohorts of patients included in HCC surveillance programs. Environmental factors will be comprehensively characterised in an ongoing clinical trial designed to evaluate alternative methods for early-stage HCC detection. Finally, AI models, reaching the minimal viable product stage by the end of GENIAL, will be used to integrate genetic and non-genetic information (including digital imaging) to develop novel, cost-effective strategies towards prevention and early-stage detection of ALD-HCC in at-risk individuals. This action is part of the Cancer Mission cluster of projects on ‘Understanding’.



*GENIAL, kick-off meeting, Group Picture*

## IP-Cure-B, General Assembly

The IP-Cure-B General Assembly occurred on March 28-29, 2023. All the Principal Investigators and scientists involved in the project gathered in Milan to discuss the progress made in the framework of the project. ELPA representatives presented data and results in the framework of communication and dissemination being involved in the WP dedicated to these activities. The meeting



*Prof Dr Pietro Lampertico M.D., Principal Investigator - Marko Korenjak, ELPA President – Prof Dr Fabien Zoulim M.D., Principal Investigator, IP-cure-B General Assembly*

was a great opportunity to exchange views and push the development of novel curative concepts for chronic hepatitis B (CHB).



*Marko Korenjak, ELPA President, IP-cure-B General Assembly*



*IP-cure-B General Assembly, Group Picture*

## LiverScreen review meeting

On April 12, 2023, ELPA took part in a meeting organised in the framework of the LiverScreen project to assess its status. LiverScreen project will screen a total of 30.000 people recruited from different European countries. By analysing the results from the 30.000 subjects recruited, the LiverScreen consortium can validate the diagnostic accuracy, cost-effectiveness and acceptability of using the TE technology to case-find advanced liver fibrosis in the general population. Moreover, LiverScreen will assess the prevalence of liver fibrosis within certain subpopulations based on health risk factors and will use this knowledge to fine-tune the case-finding. At project completion, we aim to have a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation. The LiverScreen project will achieve its goal by the following specific sub-objectives:

- Validate the diagnostic accuracy of TE to screen for liver fibrosis in the general population and primary care, using liver biopsy as gold standard.

- Assess the prevalence of significant fibrosis as evidenced by increased liver stiffness in the general population and stratified according to subjects at risk for liver fibrosis.
- Identify optimal screening intervals and define population subgroups at the highest risk of progressive liver fibrosis with the aim of designing the ideal screening strategy.
- Create a medical-decision support prognostic model (in the form of a digital tool) of liver fibrosis and estimate the long-term effects of screening for chronic liver disease.
- Estimate the incremental cost-effectiveness ratios of the screening program for different populations or groups and the budget impact on healthcare systems.
- Develop and evaluate a tailored screening program for four pilots in EU countries, representative of the different European healthcare systems.

## A-TANGO General Assembly

On September 26, 2023, ELPA attended the A-TANGO General Assembly as one of the project's partners. Everyone's progress was presented and the details of the planned start of the clinical G-TAK study. Besides updates on all work packages (WPs), participants also discussed current financial issues and decided on mitigation measures to move the project forward. The early-career scientists (ECS) programme was a highlight again! Prof. Isabelle Durand-Zaleski (APHP) gave a fascinating and insightful Masterclass lecture on "Health Economics in Liver Disease" and Annarein Kerbert (LUMC) presented the progress of the ancillary studies and related manuscripts.

## LIVERRATION Kick-off meeting

ELPA is part of the new medical, scientific project LIVERRATION, Unravelling the impact of Radiofrequency in liver surgery: the key to decrease local recurrence?, responsible for communication and dissemination. Colorectal cancer (CRC) ranks fourth in cancer deaths worldwide. Between 20% and 30% of patients with advanced CRC have liver metastases (CRLM). Liver cancer ranks second in cancer deaths worldwide, including hepatocellular carcinoma (HCC). Despite recent advances, liver resection offers the only chance of cure for patients with liver metastases. However, the recurrence rate of these tumours is high even after post-resection. The presence of positive margins in the remaining liver after resection correlates with increased local recurrence and decreased overall survival, the only factor where prognosis could be influenced by the performance of surgery. However, at present, the extent of an R-negative status remains debatable and varies widely from one publication to another. Currently, there are radiofrequency ablation studies that, based on preliminary retrospective human clinical trials, are able to correlate additional coagulation of tumour margins with a reduction in local recurrence. However, there is no prospective and pragmatic controlled study that accurately measures this additional margin and its impact on oncological outcomes. The aim of LIVERRATION is to conduct an ambitious, pragmatic multicenter clinical trial with 720 patients with CRLM and HCC at 24 clinical centres in 6 different countries to determine whether additional ablated margin produced by radiofrequency can decrease the recurrence rate and improve patient survival. We will also evaluate the patient-centredness of the intervention and its comparativeness with other therapeutic alternatives in terms of quality of life and patient experience in real-world settings. To this end, the consortium has been formed by highly experienced, highly qualified and multidisciplinary entities to carry out the project successfully. The results will not only have a major impact on a social and

scientific level but also on an economic level for the EU. This action is part of the Cancer Mission cluster of projects on 'Diagnosis and treatment'.

## The 5<sup>th</sup> DECISION General Assembly

Members of the DECISION Consortium meet in Padova, Italy, to discuss recent research results on the pathophysiology of acute decompensation of cirrhosis and development of acute-on-chronic liver failure (ACLF) – a syndrome associated with high short-term mortality. After three years of intensive work, the upcoming COMBAT trial will use newly identified biomarkers to predict disease progression and test safety and effectiveness of a combinatorial drug therapy. The DECISION General Assembly was held on 18–20 October 2023 and run in a hybrid format from Padova, Italy. This annual meeting is meant to bring together members of partner institutions to review project progress and help researchers to put their results into perspective; sharing their findings contributes to adding clarity to the studies carried out within the project and set the direction to achieve expected project outcomes. Decompensated cirrhosis is an advanced form of cirrhosis of the liver associated with development of ascites, hepatic encephalopathy, gastrointestinal hemorrhage, and progression to acute-on-chronic liver failure (ACLF). Despite multiple treatments, mortality in patients with decompensated cirrhosis remains high. The EU-funded DECISION project aims to understand the pathophysiology of decompensated cirrhosis leading to ACLF and to decrease patient mortality. This project will integrate results of high-throughput multi-omic profiling with comprehensive clinical data from 2200 fully characterised patients with available standardised biological samples. DECISION will help to identify novel combinatorial therapies to prevent high mortality for patients with decompensated cirrhosis. Combinatorial therapies will be optimised in novel animal models, and the best combinations will be tested in patients at high risk of progressing to ACLF in a phase II clinical trial.



*The 5th DECISION General Assembly, Group Picture*

The primary objective of the COMBAT trial – A novel combinatorial therapy with albumin and enoxaparin in patients with decompensated cirrhosis at high risk of poor outcome – is to determine if a combinatorial therapy based on the administration of human albumin and enoxaparin is safe and effective in patients with decompensated cirrhosis discharged from the hospital. ClinicalTrials.gov Identifier: NCT05895136.

## Liveration and Genial laymen events

On November 21, 2023, ELPA together with its scientific partners organised 2 laymen event in the framework of Liveration and Genial, EU funded projects focusing on liver cancer. The two sessions aimed at explaining the scopes of the two projects to all ELPA members.

**Liveration:** Colorectal cancer (CRC) ranks fourth in cancer deaths worldwide. Between 20% and 30% of patients with advanced CRC have liver metastases (CRLM). Liver cancer ranks second in cancer deaths worldwide, including hepatocellular carcinoma (HCC). Despite recent advances, liver resection offers the only chance of cure for patients with liver metastases. However, the recurrence rate of these tumours is high even after post-resection. The presence of positive margins in the remaining liver after resection correlates with increased local recurrence and decreased overall survival, the only factor where prognosis could be influenced by the performance of surgery. However, at present, the extent of an R-negative status remains debatable and varies widely from one publication to another. Currently, there are radiofrequency ablation studies that, based on preliminary retrospective human clinical trials, are able to correlate additional coagulation of tumour margins with a reduction in local recurrence. However, there is no prospective and pragmatic controlled study that accurately measures



**Genial-First Layman Video**

*Prof Dr Eric Trépo M.D., Principal Investigator, GENIAL 1st laymen event*

this additional margin and its impact on oncological outcomes. The aim of LIVERATION is to conduct an ambitious, pragmatic multicenter clinical trial with 720 patients with CRLM and HCC at 24 clinical centres in 6 different countries to determine whether additional ablated margin produced by radiofrequency can decrease the recurrence rate and improve patient survival.

**Genial:** The aim is to 1) portray genetic and environmental determinants promoting Alcohol-related hepatocellular carcinoma (ALD-HCC); 2) evaluate how they interact at the cellular level in human samples and preclinical models to get novel insights into liver carcinogenesis and identify chemopreventive targets; and 3) assess how these determinants modulate the ALD-HCC risk in prospective cohorts of patients included in HCC surveillance programs. Environmental factors will be comprehensively characterised in an ongoing clinical trial designed to evaluate alternative methods for early-stage HCC detection. Finally, AI models, reaching the minimal viable product stage by the end of GENIAL, will be used to integrate genetic and non-genetic information (including digital imaging) to develop novel, cost-effective strategies towards prevention and early-stage detection of ALD-HCC in at-risk individuals.

## Liverscreen general assembly

As partner of the consortium, on November 27, 2023, ELPA took part in the Liverscreen project general assembly. Liverscreen project will screen a total of 30.000 people recruited from different European countries. By analysing the results from the 30.000 subjects recruited, the Liverscreen consortium can validate the diagnostic accuracy, cost-effectiveness and acceptability of using the TE technology to case-find advanced liver fibrosis in the general population. Moreover, Liverscreen will assess the prevalence of liver fibrosis within certain subpopulations based on health risk factors and will use this knowledge to fine-tune the case-finding. At project completion, we aim to have a targeted, population-based screening intervention program for chronic liver diseases in Europe, ready for implementation. The Liverscreen project will achieve its goal by the following specific sub-objectives:

- Validate the diagnostic accuracy of TE to screen for liver fibrosis in the general population and primary care, using liver biopsy as gold standard.
- Assess the prevalence of significant fibrosis as evidenced by increased liver stiffness in the general population and stratified according to subjects at risk for liver fibrosis.
- Identify optimal screening intervals and define population subgroups at the highest risk of progressive liver fibrosis with the aim of designing the ideal screening strategy.
- Create a medical-decision support prognostic model (in the form of a digital tool) of liver fibrosis and estimate the long-term effects of screening for chronic liver disease.
- Estimate the incremental cost-effectiveness ratios of the screening program for different populations or groups and the budget impact on healthcare systems.
- Develop and evaluate a tailored screening program for four pilots in EU countries, representative of the different European healthcare systems.

## Liveration meeting

On December 13, 2023, ELPA participate in a Liveration meeting with all the partners involved in the project. Colorectal cancer (CRC) ranks fourth in cancer deaths worldwide. Between 20% and 30% of patients with advanced CRC have liver metastases (CRLM). Liver cancer ranks second in cancer deaths worldwide, including hepatocellular carcinoma (HCC). Despite recent advances, liver resection offers the only chance of cure for patients with liver metastases. However, the recurrence rate of these tumours is high even after post-resection. The presence of positive margins in the remaining liver after resection correlates with increased local recurrence and decreased overall survival, the only factor where prognosis could be influenced by the performance of surgery. However, at present, the extent of an R-negative status remains debatable and varies widely from one publication to another. Currently, there are radiofrequency ablation studies that, based on preliminary retrospective human clinical trials, are able to correlate additional coagulation of tumour margins with a reduction in local recurrence. However, there is no prospective and pragmatically controlled study that accurately measures this additional margin and its impact on oncological outcomes. The aim of Liveration is to conduct an ambitious, pragmatic multicenter clinical trial with 720 patients with CRLM and HCC at 24 clinical centres in 6 different countries to determine whether additional ablated margin produced by radiofrequency can decrease the recurrence rate and improve patient survival.

## **IP-Cure-B, Steering Committee**

On January 17, March 7, April 18, May 30, September 26, 2023, ELPA took part in the meetings of the IP-Cure-B Steering Committee. The project's objective is to develop novel curative concepts for chronic hepatitis B (CHB). Within the medical research project IP-cure-B, ELPA is responsible for disseminating and communicating the research results and any other information that can benefit patients and patient communities. ELPA is actively engaged in translating the project results and milestones into "patient-friendly" language and incorporating the patient view during the dissemination process. ELPA is also consulted to ensure that the ethics documents, information sheet and patient consent form for the proof of concept (PoC) clinical trial are understandable by patients. The process of dissemination and communication involves all ELPA's communication channels, and we actively participate in all events organised by the medical research project IP-cure-B. ELPA participated in the creation of webpage social media platforms and made sure of their updates with relevant information.

## LIST OF IP-Cure-B CLINICAL TRIAL SITES

| HOSPITAL   | HEAD OF DEPARTMENT  | PRINCIPAL INVESTIGATOR  | ADDRESS  |
|--|---|---|--|
| Hospices Civils de Lyon (France)   | Pr. Fabien ZOULIM<br><i>fabien.zoulim@inserm.fr</i>             | Pr. Fabien ZOULIM<br><i>fabien.zoulim@inserm.fr</i><br><br>Telephone (secretary):<br>04 26 10 93 55<br><br>Carrie Newsom,<br>Study coordinator<br><i>carrie-lynn.newsom@chu-lyon.fr</i><br><br>Telephone:<br>04 26 73 28 35 | Hepatology Department<br>103 Grande Rue de la Croix-Rousse<br>69004 Lyon<br>France   |
| Universitat Klinikum in Freiburg (Germany)                                 | Pr. Robert THIMME<br><i>robert.thimme@uniklinik-freiburg.de</i> | Pr. Robert THIMME<br><i>robert.thimme@uniklinik-freiburg.de</i>   | Department of Internal Medicine<br><br>Clinic for Internal Medicine II - Gastroenterology, Hepatology, Endocrinology and Infectiology<br><br>Hugstetter Street 55<br>79106 Freiburg<br>Germany |
| Hôpital Saint-Joseph (France)  | Pr. Marc BOURLIERE<br><i>mbourliere@hopital-saint-joseph.fr</i> | Pr. Marc BOURLIERE<br><i>mbourliere@hopital-saint-joseph.fr</i>   | Hepato-gastroenterology department<br>26 boulevard de Louvain<br>13285 Marseille Cedex 8<br>France   |
| Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico in Milan (Italy) | Pr. Pietro LAMPERTICO<br><i>pietro.lampertico@unimi.it</i>      | Pr. Pietro LAMPERTICO<br><i>pietro.lampertico@unimi.it</i>  | Gastroenterology and Hepatology Division<br>Via Francesco Sforza 35<br>20122 Milan<br>Italy  |
| University Hospital of Parma (Italy)                                       | Pr. Ovidio BUSSOLATI<br><i>ovidio.bussolati@unipr.it</i>        | Pr. Carlo FERRARI<br><i>carlo.ferrari@unipr.it</i>  | Department of General and Specialized Medical Area<br>Azienda Ospedaliera Universitaria di Parma<br>Via Gramsci 14<br>43126 Parma<br>Italy   |





# **SOCIAL MEDIA ACTIVITIES**



**SOCIAL MEDIA ACTIVITIES** Report by Milan Mishkovikj

Many supporters from all over the world

**ELPA Website**

TOTAL VISITS:

1,027,850

**Twitter**

FOLLOWERS

10,230

NEW FOLLOWERS

965

**Facebook**

FOLLOWERS

2,971

**Twitter, Facebook****& Others**

IMPRESSIONS

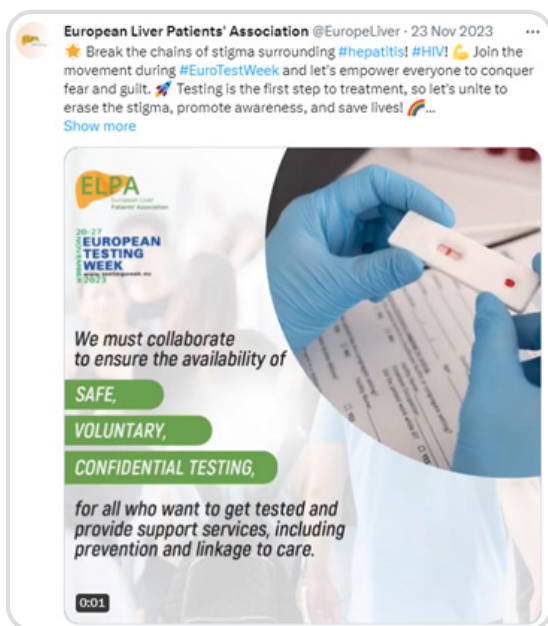
2 Billion



# ELPA's most successful Social Media Campaigns

## #EuroTestWeek - Spring and Autumn edition





## World Cancer Day

In 2023 ELPA celebrated, as every year, World Cancer Day on February 4. However, ELPA decided to go beyond World Day and run a longer campaign. The purpose was to establish a focus on liver cancer in the framework of a broader message. This goal was also pursued through the division of the messages into different categories such as data, scientific information, lifestyle, EU health policy. This assured a complete coverage of the topic.



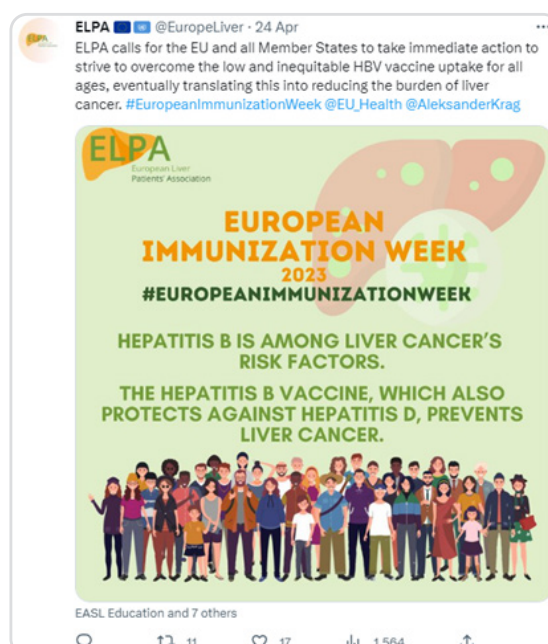
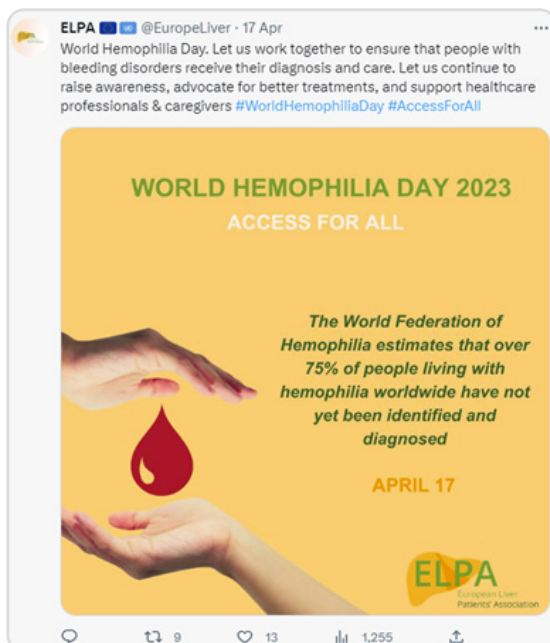


## World Obesity Day

On March 4, 2023, ELPA President, ELPA Vice President and the Leader of the ELPA Fatty Liver Working Group endorsed World Obesity Day.



## ELPA's support to its members, stakeholders, supporters and friends' campaigns





















# **ELPA STRUCTURE**








## ELPA Board of Directors

|   |                                     |   |                 |
|---|-------------------------------------|---|-----------------|
| President                                   | Marko Korenjak, M.A., M.A., M.A.    |  | Slovenia        |
| Vice-President                              | Julio Burman                        |  | Israel          |
| Vice-President                              | Dr. Tove Frisch Ph.D.               |  | Sweden          |
| Vice-President and ELPA Treasurer           | Ivana Dragojević                    |  | Serbia          |
| ELPA Director                               | MSc. Milan Mishkovikj               |  | North Macedonia |
| ELPA Director                               | Prof. Dr. Gamal Shiha M.D.          |  | Egypt           |
| ELPA Director & Scientific Committee leader | Dr. Teresa Casanovas Taltavull M.D. |  | Spain           |

## ELPA Scientific Committee

|                             |                                     |   |                      |
|-----------------------------|-------------------------------------|---|----------------------|
| Scientific Committee leader | Dr. Teresa Casanovas Taltavull M.D. |  | Spain                |
|                             | Dr. Helena Glasová M.D.             |  | Slovakia             |
|                             | Dr. Reham Soliman M.D.              |  | Egypt                |
|                             | Dr. Salvatore Piano M.D.            |  | Italy                |
|                             | Dr. Vesna Lučić- Samardžija M.D.    |  | Bosnia & Herzegovina |
|                             | Dr. Sabela Lens M.D.                |  | Spain                |







## ELPA Advisors

|                                 |   |          |
|---------------------------------|---|----------|
| Richard Hall                    |  | UK       |
| Greg Bologna                    |  | USA      |
| Dr. Marco Greco Ph.D.           |  | Belgium  |
| Prof. Dr. Rui Tato Marinho M.D. |  | Portugal |
| Prof. Shira Zelber-Sagi Ph.D.   |  | Israel   |

## Editorial Team

|        |                              |   |        |
|--------|------------------------------|---|--------|
| Leader | Dr. Hilal Ünalmiş Duda Ph.D. |  | Turkey |
|--------|------------------------------|---|--------|

## ELPA Brussels office

|                                   |                        |   |                |   |         |
|-----------------------------------|------------------------|---|----------------|---|---------|
| Head of EU affairs                | Veronika Všetíčková    |  | Czech Republic |  | Belgium |
| Head of ELPA office               | Beatrice Credi         |  | Italy          |  | Belgium |
| Events and administration officer | Anastassiya Semeiskaya |  | Kazakhstan     |  | Belgium |








# **ELPA WORKING GROUPS**



In 2023, ELPA officially had nine Working Groups. Headed by a leader, each Group can count up to 5 members. ELPA Working Groups are a way to create Expert Patients in a specific field of liver diseases.

## ELPA Working Group on Rare Liver Diseases

|         |                                     |   |         |
|---------|-------------------------------------|---|---------|
| LEADER  | Sindee Weinbaum                     |  | Israel  |
| MEMBERS | Richard Hall                        |  | UK      |
|         | Lone McColaugh                      |  | Denmark |
|         | Tarja Teitto-Tuckett                |  | Finland |
|         | Eduardo Lopez                       |  | Spain   |
|         | Dr. Teresa Casanovas Taltavull M.D. |  | Spain   |

In 2023, the Group coordinated many campaigns on ELPA channels: Facebook, Twitter, Instagram, and YouTube.

- Rare Liver Disease Week.
- International PBC Day social media awareness campaign.
- PFIC International Day social media awareness campaign.
- Global PSC Awareness Day: social media awareness campaign, 'Unmet needs of PSC patients', roundtable discussions with physicians and PSC patient organisations from around the world.






Also, the group actively participated in many events.

- Co-organisers of the Wilson's disease event, Brussels – Driving EU policy change for people living with rare diseases: a focus on Wilson's disease – Living with Wilson's disease – the patient perspective, The role of patients in improving Wilson's disease health outcomes.
- PBC International Summit, Edinburgh – Hierarchy of Patient's needs, Quality of Life, Innovations on Patient care pathway, PBC care in 2023.
- PSC Forum, Vienna - Forum for Collaborative Research: Connecting the Clinic with Drug Development. Gaps and Barriers: Reflecting on Ongoing Programs, Collaborations Across Datasets: Next Steps.
- PBC Treatment Symposium, Vienna - Unmet Needs in PBC, Case-Based Discussion on Biochemical Normalisation, Case-Based Discussion on Quality of Life and Pruritus.
- PSC Forum, Boston – Remote Participation – Forum for Collaborative Research.

Working with the clinical trials Working Group, the group explained clinical trials and the importance of participating in helping find a cure and/or treatment.

The engagement with all major PSC support groups worldwide: USA, Canada, Australia, UK, Spain, France, Italy, Norway, Denmark, Finland, North Macedonia, and Israel continued. In addition, the Group renewed its commitment as part of the Wilson's Disease Steering Committee and the collaboration with the GLI – Pediatric Rare Disease Council.

## ELPA Working Group on Primary Liver Cancer

|         |                                     |   |                 |
|---------|-------------------------------------|---|-----------------|
| LEADER  | Dr. Teresa Casanovas Taltavull M.D. |  | Spain           |
| MEMBERS | Lone McColaugh                      |  | Denmark         |
|         | Sindee Weinbaum                     |  | Israel          |
|         | Marko Korenjak                      |  | Slovenia        |
|         | Milan Mishkovikj                    |  | North Macedonia |

Liver cancer is a significant health problem around the world and its incidence is increasing. Hepatocellular carcinoma (HCC) represents 80-90% of primary liver cancer, and it is considered one of the leading causes of cancer-related deaths worldwide. Cholangiocarcinoma (CCA) is also a primary liver cancer; however, it is regarded as a rare cancer. The majority of cases of liver cancer develop in a liver with advanced liver disease, fibrosis/cirrhosis, and the origin of this liver disease is a virus, alcohol, or fatty liver. Liver cancer is potentially prevented with vaccination (hepatitis B), anti-viral treatment (hepatitis C) and appropriate lifestyle with a healthy diet, physical exercise and avoiding toxins such as alcohol.

Moreover, liver diseases are not well known and have been asymptomatic for many years. Being aware of all of this, at present, this Working Group considers that when Liver Cancer is diagnosed, only approximately 30% or less of patients are diagnosed at an early stage and eligible for potentially curative therapies. Therefore, and because liver cancer is a diagnosis with a very bad prognosis, ELPA and other groups are working to involve politicians in liver cancer programs and issues related to obesity and alcohol and to support and inform patients and families about prevention and new clinical research.




Although more treatments are available for intermediate and advanced stages, improving survival and quality of life, in ELPA, we consider crucial the information about liver cancer prevention and early screening in patients who we know are at risk. The early detection and link to care for liver cancer in specialised centres for diagnosed patients is very much needed by citizens in Europe. Considering CCA, which is a rare tumour, much work needs to be done on diagnosis and therapies, considering that it is a tumour with a heterogeneous origin and a bad prognosis.

Among the most remarkable 2023 Group's achievements, it should be listed:

- The EASL Liver Cancer Summit 2023. ELPA participated, representing the liver patient's voice. We had the opportunity to share experiences with hepatologists, surgeons, oncologists, nurses and patients.
- The group organised Liver Cancer Awareness Month, a social media campaign, a high-level meeting in the European Parliament and European Liver Screening Week.
- ELPA is participating in the redaction of the new Liver Lancet Commission of Hepatology in primary care, focusing on education and prevention.
- ELPA is also actively participating through a Delphi process in the Clinical Practice Guidelines on the management of Hepatocellular Carcinoma.

- ELPA participated as a panellist, giving the voice of the patient in the meeting “THE BCLC 2023 update Tackling the complexity of liver cancer management” in Barcelona. Teresa Casanovas presented ‘The multidisciplinary board for an optimal patient journey’.
- The Group is also building advocacy actions revolving around Steatotic Liver Disease, alcohol, obesity, and rare liver diseases.

## ELPA Working Group on Clinical Trials

|         |                                     |   |        |
|---------|-------------------------------------|---|--------|
| LEADER  | Julio Burman                        |  | Israel |
| MEMBERS | Dr. Teresa Casanovas Taltavull M.D. |  | Spain  |
|         | Yiannoula Koulla                    |  | Cyprus |

They met several times virtually and put together their work plan for 2023. The group was also in contact with pharmaceutical companies. It was responsible for collecting and researching clinical trials in various countries to help ELPA members with up-to-date information. They would like to list clinical trials on ELPA members' websites. They participated in many meetings and webinars about this topic, and two members of the Group, after enrolling in the EUPATI Fellow Programme 2021, graduated as EUPATI Fellow in 2022. The group is constantly in touch with pharmaceutical companies to keep the clinical trial list updated for all ELPA members. They contributed to organising the ELPA Clinical Trials programme on Fatty Liver, a peer-to-peer educational programme to boost the ELPA members knowledge about this topic.

## ELPA Working Group on Harm reduction

|        |                |   |        |
|--------|----------------|---|--------|
| LEADER | Aleksey Lakhov |  | Russia |
|--------|----------------|---|--------|

Harm reduction refers to policies, programs, and practices that aim to minimise adverse health, social and legal impacts associated with drug use, drug policies, and drug laws. Harm reduction is grounded in justice and human rights - it focuses on positive change and working with people without judgment, coercion, discrimination, or requiring that they stop using drugs as a precondition of support. Harm reduction is well-evidenced to prevent diseases such as HIV, viral hepatitis, and tuberculosis, among others. In 2023, the ELPA Working Group on Harm reduction made significant strides in advancing its mission to mitigate the negative consequences of substance use. The group focused on implementing evidence-based interventions and fostering collaborations with diverse stakeholders to promote harm reduction strategies. Activities included community outreach programs, educational initiatives, and policy advocacy to raise awareness about the importance of harm reduction. Additionally, the group worked towards destigmatising substance use disorders and enhancing access to harm reduction services. Looking ahead to 2024, the Group remains committed to expanding its efforts. Plans include the development of innovative harm reduction programs, continued advocacy for policy reforms, and the establishment of partnerships to strengthen their impact on individuals and communities affected by substance use further. The group is dedicated to building a safer and more supportive environment, prioritising the well-being of those struggling with substance use issues.

## ELPA Working Group on Steatotic Liver Disease (SLD)

|         |                                     |   |          |
|---------|-------------------------------------|---|----------|
| LEADER  | Yiannoula Koulla                    |  | Cyprus   |
| MEMBERS | Lone McColaugh                      |  | Denmark  |
|         | Sindee Weinbaum                     |  | Israel   |
|         | Alaia Rotaecche                     |  | Spain    |
|         | Tarja Teitto-Tuckett                |  | Finland  |
|         | Veronika Všetíčková                 |  | Slovenia |
|         | Dr. Teresa Casanovas Taltavull M.D. |  | Spain    |
|         | Dr. Reham Soliman M.D.              |  | Egypt    |
|         | Selly Sickout                       |  | France   |

For the entire year, the members were very active and held their own events with the aim of solving and preventing the problem of disease in their own country. At the EU and international level, in 2023, the team set its goals and objectives, which were:

- 1) The name of the disease and the stigmatisation of the patient.
- 2) Early diagnosis-prevention. Protect the children.
- 3) Risk Factors of the disease. (obesity, cardiovascular care).

The work was developed through the following areas:

### Research & development

- The survey under the name Socrates was finished. The outcome of this survey was crystal clear. Patients do not want the name NON- Alcoholic Fatty Liver Disease as it stigmatises them.
- The Group supported the movement to change the name of the disease.
- Involvement in 'A multisociety Delphi consensus statement on new fatty Liver disease nomenclature'.
- Few days later the EASL Congress in Vienna ALEH, AASLD, EASL and ELPA announced that steatotic liver disease SLD was chosen as an overarching term to encompass the various aetiologies of steatosis. All members of the ELPA working group played an important role in this decision.
- Delphi survey (Dr. Teresa Casanovas & Yiannoula Koulla)
- Article by Dr Reham Soliman

### Policy & Awareness

- Meeting with MEPs EU Health policy & advocacy Brussels
- World Obesity Day Patient Summit NAFLD zoom meeting: Connecting the risk factors with Fatty Liver Disease

- Virtual meeting with the EU Commissioner Ms.Stella Kyriakides (presentation) risk factors
- Slovak Medical university (Risk factors) & Primary care physicians' awareness
- NASH -NIT Summit Barcelona. Describing the pathway of a Liver patient with fatty liver disease. The important role of Primary care physicians.
- NASH summit at European parliament in Brussels and presentation of the Manifesto.
- The whole June was Fatty Liver month. All members gave their own announcements through ELPA social media in the framework of a social media awareness campaign.

## Coalitions among stakeholders




With the help and support of ELPA, the Group came in contact with various stakeholders and Associations.

## Knowledge brings strength

The members of this group have participated in many international and national seminars and ELPA educational meetings to be updated about the disease and advocate at their best for these patients.

- Patient pathway. A tele meeting (NORDICK Medical symposium)
- ELPA meetings in Malta
- The effects of the high-risk factors – hepatocellular cancer

## ELPA Working Group on Prevention

|         |                  |   |          |
|---------|------------------|---|----------|
| LEADER  | Ivana Dragojević |  | Serbia   |
| MEMBERS | Julio Burman     |  | Israel   |
|         | Marko Korenjak   |  | Slovenia |

Primary prevention examines the phenomenon's assumptions, conditions, and causes and looks for ways to avoid them. Secondary prevention seeks to prevent the deepening of the spreading. It focuses on particularly vulnerable groups such as young people, minorities, or the socially disadvantaged. Tertiary prevention aims to prevent a recurrence. This group aims to promote prevention as a critical piece of the puzzle. We are trying to do that by developing two projects, HepFreeBadge -education of professionals in the beauty parlours and Women and HBV.

Long-term goals for the project HepFreeBadge are:

- Standardization of procedures in beauty parlours according to EU standards-sterilization protocol. Modernisation and increasing the level of service in beauty parlours.
- Extension of statutory regulations regarding additional controls that include sterilisation control.
- Reducing the possibility of transmitting viral hepatitis infection while providing services in beauty parlours and decreasing stigma and discrimination.


Women and HBV project will focus on women, who are someone's girlfriends, wives, and mothers, through 12 topics. So, the target group is women, but the focus is on the general population. The content of the given topic will be adapted to an ordinary woman without incomprehensible medical terms and focused on real-life situations.

## ELPA Working Group on Hepatitis B Elimination

|         |                  |   |         |
|---------|------------------|---|---------|
| LEADER  | Ivana Dragojević |  | Serbia  |
| MEMBERS | Marinela Debu    |  | Romania |















Knowledge and awareness about Hepatitis B (HBV) have always been at the core of the association and a priority for its members. ELPA has been working on Hepatitis elimination since its creation. However, this Working Group, formally established in 2019, has been collecting updated and relevant information to push forward Hepatitis B elimination and achieve this goal in collaboration with other Working Groups. This group aims to provide tools for chronic HBV patients to live their lives as safely as possible.

## ELPA Working Group on Cirrhosis

|         |                |   |          |
|---------|----------------|---|----------|
| LEADER  | Marko Korenjak |  | Slovenia |
| MEMBERS | Julio Burman   |  | Israel   |

It has been a committed and worthwhile experience to work at the Working Group for Cirrhosis as a member of the European Liver Patient Association in 2023. The Group actively participated in multiple conversations addressing the intricate problems related to cirrhosis in an effort to enhance the quality of life for patients. One noteworthy accomplishment was growing the number of EU-funded initiatives in which ELPA is involved; several of these studies have the potential to improve the lives of people with cirrhosis significantly. The Group participated in a number of ELPA events, bringing attention to the serious issues surrounding cirrhosis in relation to viral infections like HBV and HCV and the potential for liver cancer. To improve patient advocacy, members kept a close eye on articles about cirrhosis. By taking part in ELPA's EU strategic screening week, the Group was able to locate and assist people with cirrhosis who needed help. Members aggressively promoted cirrhosis awareness towards the close of the year, concentrating on alcohol consumption throughout Europe. The Group stays steadfast in its commitment as it looks ahead to 2024. It will keep working to increase awareness, particularly on the problems associated with alcohol misuse in Europe. As the Group works towards a better future for cirrhosis patients throughout Europe, it will continue to actively participate in all ELPA events that are directly related to the disease.

## The multicultural ELPA Working Group

|         |                                    |   |        |
|---------|------------------------------------|---|--------|
| LEADER  | Dr Tove Frisch Ph.D.               |    | Sweden |
| MEMBERS | Dr Teresa Casanovas Taltavull M.D. |    | Spain  |
|         | Eduardo López                      |    | Spain  |
|         | Prof Dr Gamal Shiha M.D.           |    | Egypt  |
|         | Sindee Weinbaum                    |    | Israel |
|         | Richard Hall                       |    | UK     |
|         | Dr Hilal Unalmış Duda Ph.D.        |    | Turkey |
|         | Prof Dr Soo Aleman M.D., Ph.D.     |    | Sweden |
|         | Dr Erik Baecklund                  |    | Sweden |
|         | Penilla Gunther                    |    | Sweden |
|         | Farhad Khaghani                    |    | Iran   |
|         |                                    |  | Sweden |
|         | Esso Ouro-Nimini                   |    | Togo   |
|         |                                    |  | Sweden |

The Focus of this new group is:

- 1) Find best and worst practices in the different countries and health care areas, compare them.
- 2) Find the attitudes and expectations among patients and health care workers, compare them.
- 3) The goal of this path as well as the knowledge and understanding emerging from this work is to prevent people from getting ill or worse and thereby improving the life and the course of disease for the patients in all involved countries.

### Method:

The group agreed to do a survey in English and Swedish since some of the people in Sweden are not used to English. The survey would go to all the people in this group but also to patients or people with multicultural experiences outside the group, so the number of interviews and interviewees will exceed the number of members in this group. The survey is one method; the other is to visit all the countries, go to clinics or organisations and see how they work to broaden the picture from the survey. Almost all interviews in Sweden are finished. A few were left for. Vision for 2024: Visit all the 6 countries in the group, look at the work done and interviewing adequate persons.





# **FINANCIAL ACCOUNTING AND TRANSPARENCY**



## Word from ELPA Treasurer

The financial position of the European Liver Patients' Association remained strong in the fiscal year 2023. ELPA achieved this through wise expense management combined with a successful fundraising performance.

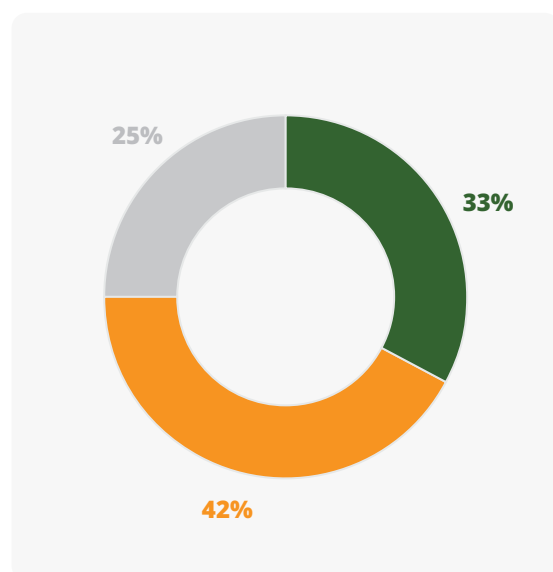
The fundraising activities conducted during 2023 made the association less dependent on pharmaceutical companies' contributions, expanding the proportion of funding coming from different sources.

Ivana Dragojević, ELPA Treasurer

## Publishing financial reports

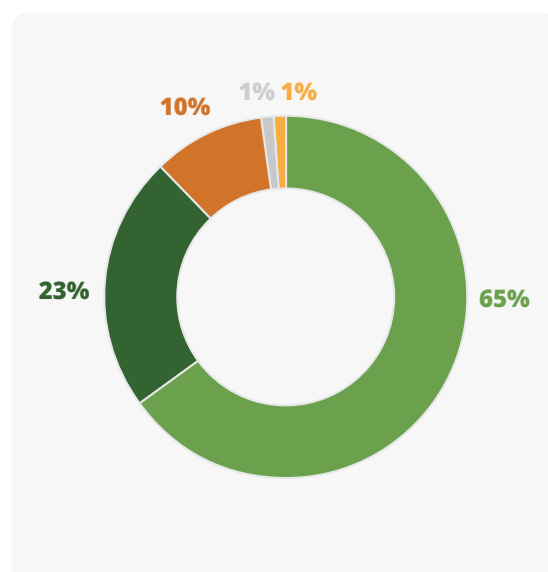
All financial reports of ELPA from 2007 are published every year and can be found on our webpage: [www.elpa.eu](http://www.elpa.eu)

### Revenue 2023



- Core funding
- ELPA's projects
- EU project

### Expenditure 2023



- ELPA work
- Operational expenses
- Wages and fees
- Depreciation
- Financial charges/income



| (EUR)  | 31/12/2023        | 31/12/2022          |
|--|-------------------|---------------------|
| <b>Assets</b>                                      |                   |                     |
| Fixed assets                                       | 37 118,83         | 44 372,47           |
| III. Tangible fixed assets                         | 33 718,83         | 40 672,47           |
| B. Plant, machinery and equipment                  | 33 470,16         | 40 164,12           |
| C. Furniture and vehicles                          | 248,67            | 508,35              |
| IV. Financial fixed assets                         | 3 400,00          | 3 700,00            |
| C. Other financial fixed assets                    | 3 400,00          | 3 700,00            |
| 2. Amounts receivable and cash guarantees          | 3 400,00          | 3 700,00            |
| Current assets                                     | 932 781,72        | 1 031 799,30        |
| VII. Amounts receivable within one year            | 5 000,00          | 7 041,26            |
| B. Other amounts receivable                        | 5 000,00          | 7 041,26            |
| IX. Cash at bank and in hand                       | 911 931,72        | 1 024 758,04        |
| X. Accruals and deferred income                    | 15 850,00         | 0,00                |
| <b>Total assets</b>                                | <b>969 900,55</b> | <b>1 076 171,77</b> |
| <b>Equity and liabilities</b>                      |                   |                     |
| Equity   | 923 176,02        | 831 232,10          |
| III. Reserves                                      | 83 470,16         | 103 552,00          |
| A. Reserves not available                          | 83 470,16         | 103 552,00          |
| 4. Other   | 83 470,16         | 103 552,00          |
| IV. Accumulated profits (+)/ losses (-)            | 839 705,86        | 727 680,10          |
| Amounts payable                                    | 46 724,53         | 244 939,67          |
| IX. Amounts payable within one year                | 29 724,53         | 34 273,00           |
| C. Trade debts                                     | 5 701,49          | 4 818,12            |
| 1. Suppliers                                       | 5 701,49          | 4 818,12            |
| E. Taxes, remuneration and social security         | 24 023,04         | 29 454,88           |
| 1. Taxes   | 12 349,03         | 18 415,19           |
| 2. Remuneration and social security                | 11 674,01         | 11 039,69           |
| X. Accruals and deferred income                    | 17 000,00         | 210 666,67          |
| <b>Total liabilities</b>                           | <b>969 900,55</b> | <b>1 076 171,77</b> |
| <b>Profit and loss account</b>                     |                   |                     |
| I. Operating income                                | 870 277,66        | 577 527,86          |
| A. Turnover  | 869 802,42        | 577 527,86          |
| D. Other operating income                          | 475,24            | 0,00                |
| II. Operating charges                              | 768 735,84        | 584 182,05          |
| A. Goods for resale, raw materials and consumables | 504 522,94        | 397 722,01          |
| 1. Purchases                                       | 504 522,94        | 397 722,01          |





|  |             |             |
|--|-------------|-------------|
| B. Services and other goods  | 175 932,29  | 114 764,08  |
| C. Remunerations, social security costs and pensions   | 78 993,13   | 64 489,49   |
| D. Amortisations of and other amounts written down on formation expenses, intangible and tangible fixed assets | 6 953,64    | 6 953,64    |
| G. Other operating charges   | 2 333,84    | 252,83      |
| III. Operating profit/loss   | 101 541,82  | -6 654,19   |
| IV. Financial income   | 8 919,08    | 16 278,71   |
| A. Income from financial fixed assets  | 242,92      | 0,00        |
| C. Other financial income  | 8 676,16    | 16 278,71   |
| V. Financial charges   | 18 516,98   | 2 737,82    |
| A. Debt charges  | 2 806,48    | 0,00        |
| C. Other financial charges   | 15 710,50   | 2 737,82    |
| VI. Profit/loss of the period before taxes   | 91 943,92   | 6 886,70    |
| IX. Profit/loss of the period  | 91 943,92   | 6 886,70    |
| X. Transfer from/to untaxed reserves   | 20 081,84   | 0,00        |
| A. Transfer from untaxed reserves  | 20 081,84   | 0,00        |
| XI. Profit/loss of the period available for appropriation  | 112 025,76  | 6 886,70    |
| Appropriation account  | 0,00        | 0,00        |
| A. Profit/loss to be appropriated  | 839 705,86  | 727 680,10  |
| 1. Profit/Loss of the period available for appropriation   | 112 025,76  | 6 886,70    |
| 0. Profits/loss of the preceding period brought forward  | 727 680,10  | 720 793,40  |
| D. Profit/loss to be carried forward   | 839 705,86  | 727 680,10  |
| 1. Profit to be carried forward  | -839 705,86 | -727 680,10 |





# **ACKNOWLEDGMENTS**



ELPA is thankful to all its members and numerous volunteers that have helped us accomplish our goals in 2022. We are also grateful to all our supporters and stakeholders. They have been backing our endeavours to fight liver disease over the years.

In 2023, ELPA received grants as well as, in some cases, in-kind support from the following companies:



# AT IPSEN, PATIENTS DRIVE US



WE WORK WITH OVER 260\* PATIENT ORGANIZATIONS WORLDWIDE ACROSS OUR  
**THREE THERAPEUTIC AREAS**

**121**

ONCOLOGY

**69**

NEUROSCIENCE

**77**

RARE DISEASE

FIND OUT  
MORE AT:

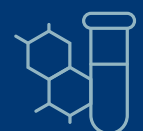
[www.ipsen.com/patients](http://www.ipsen.com/patients)  
[www.ipsenmedicalinformation.com](http://www.ipsenmedicalinformation.com)



We start the **dialogue** as early as possible with patients when developing new medicines



We **collaborate** with patient communities to develop solutions together that deliver long-term impact



We **innovate** to make a meaningful difference to patients, their families, and caregivers

\*Source: Ipsen internal patient organization database. Date of verification: 14<sup>th</sup> March 2024



Thank you

to everyone at the  
European Liver Patients' Association  
for your dedication to increasing  
understanding of liver disease  
across Europe, and your support for  
people living with rare diseases like  
primary biliary cholangitis, PBC.



CymaBay Therapeutics, A Gilead Company.

Working to improve the lives of people living with PBC.



## Transforming Lives. Every Day.

At Alexion, our mission is to transform the lives of people affected by rare diseases and devastating conditions through the development and delivery of innovative medicines, as well as through supportive technologies and healthcare services. [alexion.com](https://alexion.com)



MAUREEN AND LAUREN  
LIVING WITH LAL-D



**The liver plays a pivotal role in the body's metabolism and is a vital organ in the cardiovascular, renal, and metabolic system.**

At Boehringer Ingelheim, we are following the science to unlock meaningful medicines for people living with liver disease by addressing liver health early.

We advocate for a shift from fragmented solutions to integrated approaches that focus on prevention and treatment, to transform the lives of people with cardio, renal and metabolic conditions.

We're proud of our partnerships. Together we seek to ease the pressure on people living with these diseases, their families, and healthcare systems worldwide.



Learn more at <https://www.boehringer-ingelheim.com/human-health/metabolic-diseases>



What we do

# Driving change through scientific & digital innovation

**Marie Darting**  
Marie works in Oral Finished  
Products in Denmark





# Bayer is proud to support ELPA

Transforming the lives of **people**  
impacted by **cancer** through  
**science** and **innovation**

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## Together, let's stop chronic liver disease

Today, millions of people are silently progressing from chronic liver disease to liver cancer.<sup>1,2</sup> **This needs to change.**

Our OneLiver mission is to partner with the healthcare community to break this cycle, to help stop, or even reverse the disease. Our core expertise will continue to focus on cutting-edge diagnostics and treatment.

We look forward to our continued collaboration in 2024 and beyond with ELPA, the member organisations and partners, to make our mission a reality.

1. Cheemerla S. and Balakrishnan M. *Clin Liver Dis* (Hoboken) 2021;17:365–370.  
2. McGlynn KA, et al. *Hepatology* 2021;73(Suppl 1):4–13.



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